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1 June 19 & 22, 1998. Interview with Albert R. Jonsen, MA, STM, PhD, Professor of
2 Ethics in Medicine and Chairman, Department of Medical History and Ethics, School of
3 Medicine, University of Washington, Seattle, Washington. The interview is being
4 conducted by Judith Swazey at Professor Jonsen's office at the University of Washington.
5

6 Swazey: Let me start out with something we'll come back to, but since you are one of the
7 major figures in bioethics, I'd like to know how you think about bioethics, how
8 would you characterize it?
9

10 Jonsen: I think of it both as a discipline and a discourse. Discourse first: I think that the
11 way this field has developed, it's been very largely people talking to people. It's
12 been an increasingly extended conversation among health care providers, scholars
13 in other fields, and to some extent patients, and certainly the news media and so
14 forth. It's been a broadening conversation about a range of topics that are loosely
15 clustered around the technologies of medicine, and the provision of health care,
16 and the biological sciences as they develop. I use the word "discourse" to talk
17 about a conversation that's been given a certain shape. Conversations are given
18 shape by certain words becoming more common within them, by those words
19 acquiring general but specific definitions and by the arguments that take place
20 within that conversation having a certain structure of pros and cons. It seems to
21 me that this has been, for the past thirty years, a conversation which has shaped
22 into a discourse around the topics. For example, one can almost now predict the
23 way in which, a political debate over assisted suicide will go. We know the issues

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24 that will be brought up, we know the arguments over terminology that will arise
25 and so forth.

26 That then leads to my second characterization of bioethics. It is a
27 discipline. There has been, of course, a debate since its beginnings: whether
28 bioethics ought to be called a discipline. Dan Callahan's early article in the
29 1970's uses the term "bioethics as a discipline," and he gives some characteristics
30 of a discipline in that article. I think that it's appropriate to call it a discipline in a
31 loose academic sense. There really aren't any disciplines in the old, formal sense
32 anymore in academia. Even mathematics, classical discipline, is now splintered
33 into all sorts of special fields. So I don't think we need to have a very strict
34 definition of a discipline. A discipline, to me, basically is a "teachable,"...which
35 is its literal, etymological meaning. A "teachable" means that a group of people
36 called professors can designate a beginning, middle, and an end to a set of
37 arguments and data. I think that has come into shape. It bulges at the edges, or it
38 leaks at the edges, there's no doubt about that, but it's the way in which
39 mathematics leaks into physics and physics leaks into mathematics. It's
40 teachable, one knows now what to do when one walks into a classroom with a
41 course description that says bioethics.

42

43 Swazey: Do you think that was equally true when Dan wrote about it in the early 1970's?

44

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45 Jonsen: No, it was not true then. Dan's article talks about the future, bioethics becoming a
46 discipline rather than being a discipline. I forget exactly the characterizations he
47 gave of a discipline. I also think, along with teachability, a discipline has research
48 ability. The people who teach it want to expand and deepen their understanding
49 of the topics and the terms. They set out projects to refine that more completely
50 and, although those projects are not like a scientific protocol, some people do
51 historical research, some people do sociological research, some people do quasi-
52 epidemiological research about such things as "do not resuscitate orders." So
53 Bioethics is a discipline in the sense that it's a teachable subject and it has a
54 research dimension to it. The ultimate proof of a discipline being a discipline is
55 that somebody pays professors to teach it. So that's my general characterization
56 of the field.

57
58 Swazey: When would you say it reached that status?

59
60 Jonsen: I'd say it probably reached that status in the late 1970's, early 1980's. It was by
61 that time that many medical schools had employed faculty to teach this subject,
62 my primary criterion. At least there were enough teachers around that we could
63 communicate with each other and associate with each other. I think that the
64 Society for Health and Human Values started its faculty interest group just about
65 that time. So there was a critical mass of teachers then. The appearance of The

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66 Encyclopedia of Bioethics, several years previously, in 1976 laid out the body of
67 topics. There were a few textbooks: Gorovitz's text was out, Howard Brody's
68 text was out, Beachamp's and Childress' book appeared about 1979. And then
69 there was also growing interest in bioethics being taught in other places, medical
70 schools, university curriculum, in various departments like philosophy
71 departments, and some social science and sociology departments. So that's the
72 point where some of these critical elements of disciplinary emerged. That was
73 just about the time that Hastings had a task force on the teaching of bioethics.
74 The interesting thing about that task force was that it examined not just the
75 teaching in medical schools where it was most prominent, but also teaching in
76 high schools, teaching in universities and so forth.

77

78 Swazey: While on that general theme, what's your view about degree programs in
79 bioethics?

80

81 Jonsen: Well, I started teaching in 1972 at UCSF. I was always very hesitant and quite
82 skeptical about degree programs. That's largely because I didn't see bioethics as a
83 discipline on its own because, in those days, I had a more formal definition of
84 discipline. To me, it looked like it was an amalgam of philosophy, and theology,
85 and sociology, and the biomedical stuff. I thought at the time, that of all of those
86 bioethics should really be philosophy. That was my original prejudice. Therefore,

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87 people ought to get philosophy degrees and then learn something about medicine
88 in its practice and its social structures. I gradually changed my mind on that, first
89 of all because my understanding of discipline loosened up a lot. That probably
90 was just about the time I came to the University of Washington which was 1987.
91 Another point about the previous issue is that I've always thought of bioethics
92 largely as an adjunct to other activities in those days.

93

94 Swazey: For you professionally, or just in general?

95

96 Jonsen: In general. That it was to help doctors and patients. Therefore I didn't want it to
97 take on a life of its own. Now if one can talk of a mild conversion--this is not
98 Paul struck on the way to Tarsus--when I came here I inherited a degree program
99 that was, at that time, actually history of medicine but had mutated into ethics
100 because students were interested in it. They were taking history MA work while
101 really doing bioethics. So I inherited a degree program and I also came back into
102 a university because UCSF, as you know, is a truncated university, really a health
103 sciences research center. At UW, I was back in a university, in actual contact with
104 other disciplines, with history and philosophy and sociology. I was beginning to
105 get more liberal about what a discipline was. So just in terms of my actually
106 having a degree program at my finger tips here, and in terms of liberalization of
107 my disciplinary concept, I began to think that a degree program was a useful thing.

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108 At the same time other people were mounting degree programs fairly successfully.
109 I'd been impressed at what Georgetown was doing. Between UCSF and UW, I
110 spent a semester teaching at Georgetown before I came here, teaching in their
111 doctoral program. I thought that they had arranged things pretty well, that they
112 had a mix of philosophy and other disciplines. As I look back on it, it was
113 probably too philosophical.

114

115 Swazey: This was their intensive course?

116

117 Jonsen: No, this was their graduate program, which was in the philosophy department. I
118 taught for a semester and gave two courses to graduate students. So my
119 judgement now is that things have matured to the point where bioethics can be
120 appropriately thought of as a degree program. I still am rather skeptical about a
121 PhD for most interested students I think the PhD's, for people who are working in
122 bioethics, with a strong concentration on ought to be in classical disciplines and a
123 concentration in bioethics. But in particular, I'm beginning to think that the
124 masters degree program is an appropriate thing for a variety of people who will
125 not become professors, mostly people who are health professionals and others
126 who will be administrators at HMO's or research IRB coordinators, things of that
127 sort. The masters program now reflects the level of complexity which the
128 discipline has reached. There was a time when we could say, "Take the intensive

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129 course and you'll know enough about bioethics to be able to talk about it
130 intelligently." I think now the field is extensive enough and complex enough that
131 a masters degree is an honest acknowledgment of the breadth of that complexity.
132 And so for people who want to do that, that's what we've done here. We've
133 changed our masters program to one exclusively designed for professional people.

134

135 Swazey: A little like an MPH in that respect.

136

137 Jonsen: It's a little like an MPH, that's right. That's exactly the parallel. In fact, what we
138 were doing here for those professional people who wanted to do that more
139 intensive involvement, was giving them an MPH. It was the only degree around
140 that we could give them because our MA here was a heavily philosophically laden
141 course. So a physician would come and say, "I want to spend a year doing this."
142 We had to give him an MPH in the school of public health with a big dose of
143 bioethics. Actually they studied with us but they took the MPH degree.

144

145 Swazey: It's really sort of a generalist degree.

146

147 Jonsen: Yes. So we changed that two years ago and now we're giving an MA to health
148 professionals. Case Western does pretty much the same. I think Penn now is on
149 the verge, or maybe they've already started.

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150 Swazey: They're just starting. Who's a bioethicist? I assume you define yourself as a
151 bioethicist?

152
153 Jonsen: Yes, I do. I have a lot of fun with that, the origin of the word, where it came from
154 and all the rest. It's fun to fiddle around with. I think a bioethicist is a person
155 who is full-time employed doing the things that bioethics is. I think it's a
156 pragmatic definition. There are probably 200-300 people who have full-time jobs
157 either teaching, or counseling, or consulting. And their topics are broadly the
158 topics of bioethics. So I don't have a very fancy definition.

159
160 Swazey: Pragmatic in terms of if they're doing bioethically relevant things most of the
161 time, then they are by definition a bioethicist?

162
163 Jonsen: Yes, it's an operational definition. I would exclude the physicians and nurses who
164 studied the field and who, on occasion, consult. Let's take a concrete example.
165 Over in Boise there's a chaplain in the hospital that is affiliated with the Episcopal
166 Church, who has studied a lot of bioethics. She has come over here and taken our
167 certificate program so forth and so on. She's a chaplain, that's what she is. She
168 consults in bioethics; she's their bioethics person but her job description is the job
169 description you would expect a chaplain to have. I wouldn't consider her a
170 bioethicist. At Sacred Heart Hospital in Spokane there is a fellow who's a nurse

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171 by training, named Johnny Cox, who is full-time employed as the ethics
172 consultant. He doesn't do any nursing anymore. He's a bioethicist. It's a job
173 description more than anything else. The reason I mentioned the chaplain is that
174 she's now trying to get her hospital to rewrite her job description to include a
175 substantial piece of bioethics consultation because she says, "That's the way my
176 career has moved. People come to me as much for bioethics consultation as they
177 do for spiritual advice and liturgical activities."

178

179 Swazey: Why do you think so many people who are interested in the topics bioethics deals
180 with, and broad value questions, are defined and called a bioethicist no matter
181 what their field is?

182

183 Jonsen: I think that's in part a media phenomenon. The media has picked up on the term
184 "ethicist" or "bioethicist" and it's amazing to see it show up everywhere. Gina
185 Kolata's articles always have to have Arthur Caplan in there and Arthur is always
186 "ethicist." Now Arthur is a real ethicist but if she gets somebody else...if she
187 came to you she would probably describe you as ethicist.

188

189 Swazey: Larry Altman and Phil Hilts and others have. I have worked on bioethical topics
190 for a long time and I'm always being introduced in Maine, given its small
191 population, as the state's senior bioethicist. I sort of look around to see who they

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192 are talking about.

193

194 Jonsen: I wouldn't say that you are a bioethicist because your general field of work is
195 much, much broader than that. And Renée Fox is not a bioethicist. She is a social
196 scientist.

197

198 Swazey: She is a social scientist who works on bioethical topics.

199

200 Jonsen: There's also a certain cachet about bioethicists, which probably is a result of the
201 media's use of the term. Art and others in the field are always downplaying the
202 expertise aspect of it, saying that it's silly to think that somebody has an expertise
203 in ethics. I don't think it's silly at all. I think there are people who have a mastery
204 of the kind of discourse I described earlier. As I said, you can anticipate how a
205 conversation is going to go. Well, a non-expert doesn't anticipate how that
206 conversation is going to go, doesn't know what the next move will be. I can sit in
207 one of these debates, or discussions, or panels and listen to my previous speakers,
208 and while they're talking I create my response because I know what the moves
209 are. That's a form of expertise; I know how to play chess. What I don't claim is
210 that I can make a better ethical judgement than anybody else because in the last
211 analysis ethical judgements are highly contingent and idiosyncratic. But I could
212 probably say that when put to it, I can make a better informed ethical judgement

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213 than most other people. It may not be a better judgement, but it's a form of
214 expertise. I think that, even with the kind of skepticism and cynicism about
215 ethical expertise, there is a belief that some people can say things about ethics that
216 are more sensible than other people.

217

218 Swazey: Where does a masters degree leave you in terms of that expertise? What are you
219 equipped to do? Can you be a clinical ethicist with a masters?

220

221 Jonsen: Yes, I think so.

222

223 Swazey: You sound a little unsure.

224

225 Jonsen: Well, being a clinical ethicist requires a good deal of personal skill.

226

227 Swazey: I want to get into that in some detail because I find that a fascinating phenomenon
228 in bioethics.

229

230 Jonsen: Yes, but I think a degree can give a person the tools. I think it can give them
231 enough information to be an advisor to an institution. For example, I think a
232 person might be asked to oversee an ethics committee, and so you know pretty
233 well what an ethics committee is when you have that sort of background. Two of

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234 our graduates here have gone into IRB administration.

235

236 Swazey: Let me switch topics and get some of your professional history and entry into
237 bioethics. Let's go back to your training in theology and philosophy and see if
238 you could broadly characterize the major dimensions of that training. For
239 example, in philosophy, what kind of philosopher were you trained as?

240

241 Jonsen: This is pretty fully laid out in the preface of my book, The Birth of Bioethics. I
242 entered the Jesuit Order in 1949 when I was 18 years old. In those days, the Jesuit
243 education was a very rigorous and patterned education, traditionally extending
244 over 13 years before ordination. In those days the Jesuits educated in the old
245 fashion, in the Renaissance fashion. Students took a whole block of material
246 without mixing it with other things. So we had 2 years of humanities, which were
247 languages and literature. And then we spent three years in concentrated study in
248 philosophy. During philosophy, they also taught a few other college subjects like
249 physics and chemistry because in the Renaissance that was natural philosophy, so
250 it was okay. We had modern physics, in addition to natural philosophy. In those
251 days, (I'm talking of the very early 1950's) the Jesuit course in philosophy was a
252 course in what used to be called scholastic philosophy, which meant basically
253 reading the major works of Aristotle and Thomas Aquinas. Aquinas, of course, is
254 usually thought of as a theologian but he has major philosophical works that are

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255 commentaries on Aristotle for the most part. So I was trained in what was a fairly
256 narrow but very demanding system in which logic and rigor of argumentation, and
257 carefulness with definition were considered very important. That happened to be
258 an era in which there was an extraordinarily vital revitalization of scholastic
259 philosophy. My teachers were trained with those people such as Jacques Maritan
260 and Etienne Gilson, who were trying to take this medieval structure and relate it to
261 modern thought, to make it come into contact with existentialism and with
262 phenomenology. So we didn't just read the Middle Ages, we were reading
263 modern scholastic philosophy and modern philosophy.

264 Another feature of this modern scholasticism was a great interest in the history of
265 philosophy. That was another dimension that was of great importance.

266
267 Swazey: The history of philosophy broadly defined, or history of scholasticism?

268
269 Jonsen: No, history of philosophy broadly defined. We read the pre-Socratics, we read
270 Plato, we read Hobbes, Locke, Kant. I took a Kant seminar for a quarter and all
271 this sort of thing. We had a solid foundation in a systematic philosophical
272 approach and then we had quite a broad scope of the history of philosophy, so it
273 was a very valuable three years. I think essentially those three years of
274 philosophy were the equivalent of a PhD program, given the amount of work that
275 we did. As soon as I finished that program in 1955, I was assigned by my Jesuit

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276 superiors to teach philosophy. I taught philosophy at Loyola University in Los
277 Angeles for three years. In teaching philosophy, of course, you don't expose
278 ordinary college students to the kind of expansive and rigorous stuff that we did
279 but....

280

281 Swazey: Tempting as it was when you're starting!

282

283 Jonsen: It took me time to break the mold, you know. Those were the days when there
284 was a great deal of interest in existentialism. So I devised courses in philosophy,
285 primarily in epistemology, and in ethics, that largely were the scholastic response
286 to existentialism. That's basically the way I taught. When I finished those three
287 years I was sent back to the next phase of the Jesuit training which was four years
288 of theology. Again, that was fundamentally scholastic theology but in that case it
289 was amplified by the kind of biblical studies that were coming into focus at the
290 time. Critical biblical studies in which archeology and linguistics and so forth
291 were very important. That was the theological training which I think was also
292 very rich and very rewarding.

293 I didn't study much moral theology. There was a standard course in moral
294 theology which we all had to take for two years, which I didn't find very inspiring.
295 Well, I did find it inspiring in a negative sense because I realized that one of the
296 important things for the Catholic Church was to revitalize their moral theology in

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297 the same way that it was revitalizing its scriptural studies and its doctrinal
298 theology, which were the exciting subjects at that time. Moral theology was kind
299 of a backwater. So it was with that in mind that I began to inquire about the
300 possibility of doing some graduate studies that would help me participate in such
301 a task. In the world in which I was living, the standard way to do graduate study
302 would be to go to a Catholic University, such as Georgetown, Fordham, or St.
303 Louis University, or go to the Institute Catholique in Paris, or to go to the
304 Gregorian in Rome. I thought doing that would just leave me pretty much where I
305 was before.

306
307 Swazey: You didn't quite know how to break out of that Catholic....

308
309 Jonsen: Yes, I didn't know how to break out of that. But I did by chance learn about
310 Harvard's summer school and I asked my superiors, in my second year of
311 theology, if I could go to Harvard's summer school and take an ethics course.
312 They were liberal enough to allow me to do that. I went and I took the first course
313 that I had ever taken in metaethics, which wasn't part of the Catholic discipline.
314 And I was really astonished by what metaethics was--basically an attempt to
315 analyze ethical language in a way that was somewhat parallel to what was going
316 on in biblical studies. You lift yourself up from the page and you say, "How are
317 these words functioning?" So I took that course and I took a course in the

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318 sociology of religion. That was a fascinating course because the professor took as
319 his subject matter--I thought I was getting away from the Catholic world -- the
320 worker priests of France, a post-war phenomenon in France, within the social
321 world of French Catholicism. Absolutely fascinating course! I came back and I
322 really found myself changed by that summer school, and I asked if I could go back
323 the next year and they said yes. So I went back a second summer, took another
324 course in ethics. It wasn't a very good course mainly a review of utilitarian
325 thinkers. And I took Victor Frankl's course in logotherapy. He died recently; he
326 was a wonderful man. I had started to be, in a sense, secularized.

327
328 Swazey: Living in two different worlds...moving in two different worlds.

329
330 Jonsen: Yes! I was ordained in 1962 and it was our custom to have another year of
331 theology after that and then to have a year of retreat. I was sent to Montreal for
332 that year of retreat, which was supposed to be entirely devoted to religious and
333 spiritual things, but I was hooked now. When I was in Montreal, it was customary
334 during the period of Lent to go out and work in a church. I was in a French
335 speaking community and wasn't ready to go to a Francophone parish, so I asked if
336 I could go down to the States and find a place. I tried to get the Harvard Catholic
337 Club but they didn't have any place available. So I wrote to Yale's St. Thomas
338 Moore House, and the chaplain there said, "Yes, come on down, I'd love to have

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339 some help.” So I went down there and I met Professor Jim Gustafson. Then I
340 realized what I could do in graduate school because Gustafson was a genuinely
341 ecumenical figure. And I didn’t have to worry that I would be de-Catholicized.
342 He was very eager to have Catholic graduate students in religious studies focusing
343 on ethics. So I applied to Yale; I actually applied to the Harvard program at the
344 same time, got admitted to both on the same day. The Harvard program would
345 have been very different. Bob Veatch went through that program. It would’ve
346 been very different because there was little ecumenical interest at Harvard. The
347 professor of ethics there, James Luther Adams, was very much focused on the
348 Protestant reformation. I don’t think he would’ve known what to do with a
349 Catholic in that program. But the Yale program was absolutely marvelous for me
350 because it allowed me to explore my own tradition. In the course of the three
351 years I was at Yale, Gustafson had invited as visiting professors three of the most
352 distinguished Catholic thinkers of the time. Jesuit Robert Johann (he faded after a
353 while but at the time he was a big name) and Joseph Fuchs from Rome and
354 Bernard Häring. So I studied with each of them. Then I had a chance to explore
355 the Protestant tradition very fully. All of this was with ethics in mind, theological
356 ethics, but all of it was ethics. I was able to take a course from John Smith in
357 American pragmatism which also was a totally new experience for me, James and
358 Dewey in particular. I had, all the way through...this is a longer story than you
359 asked for, Judy!

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360 Swazey: No, it is not! It is not any bit longer because one of the things I was going to
361 specifically ask you about was your interactions with Jim Gustafson and what sort
362 of influence he had on you. You are saying a great deal.

363
364 Jonsen: I will come back to Jim's particular influence but I think that the general
365 education that I got was extraordinarily fortunate because I was able to touch on
366 almost all of the elements that go into modern bioethics long before bioethics was
367 a glimmer on the horizon. I didn't have to change a lot as I migrated into this
368 field, in terms of the skills that I think are needed to do ethics. So I probably had
369 the best education, the most relevant education, of anybody in the field, because it
370 wasn't focused within a particular discipline. For instance, Dan Callahan did a
371 philosophy program at Harvard that was very disciplined but very limited.

372
373 Swazey: So you didn't just study analytic philosophy or whatever the particular school was.

374
375 Jonsen: That's right. And as you'll see in The Birth of Bioethics, one of the fascinating
376 things is that most of the philosophers who moved into the field came out of
377 philosophy of science; almost nobody studied ethics because ethics was really a
378 dead topic. Dan Clouser did concentrate on ethics at Harvard, and Tom
379 Beauchamp did at Hopkins. Beauchamp didn't do it exclusively, he was also was
380 very interested in epistemology. At any rate, none of the theologians had the

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381 opportunity to do what I did outside the disciplinary field, except for the ones who
382 went to Yale such as Childress and Hauerwas that's not really very accurate.
383 Veatch made his own way and really created a course for himself at Harvard. So
384 he's probably as fortunate as I am in kind of making his own way. He actually
385 started with medical ethics in mind. He was interested in doing that before it
386 existed and trained himself step-by-step for it. But for the most part, other people
387 did pretty limited classical approaches to philosophy and theology. Should I talk
388 about Jim Gustafson now?

389

390 Swazey: Sure, that would be great.

391

392 Jonsen: As a teacher, he is really magisterial in the best sense. He draws his students in to
393 a problem in an extraordinary way. He never lectures at his graduate students; he
394 lectured when he taught undergraduates. I was his teaching assistant at the
395 Divinity School and he gave lectures of course. But with his graduate students it
396 was always how he could draw their minds into the problematic of the author that
397 we were reading. He insisted over and over again that we don't overlay somebody
398 else's thought with our own. What are they thinking and why are they thinking
399 what they're thinking about in their social context, in their historical context, in
400 their personal context? That was a tremendous experience; the two-year seminar
401 that all the graduate students did with him was beautiful in that respect. He would

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402 never let anybody say, "Well, in my view such and such is what Kierkegard is
403 saying." He would say, "We're not really interested in your view. What is
404 Kierkegard saying and why is he saying it the way he is?" And he drove us to
405 that. We had a fabulous class! That particular year was Jim Childress and Stan
406 Hauerwas and Jim Laney. Do you know Jim?

407

408 Swazey: No, I don't.

409

410 Jonsen: Jim Laney didn't go into ethics but almost immediately became dean of the
411 divinity school at Emory and then its president. He was president at Emory for a
412 number of years and he's the one that brought Jim down to Emory. Then
413 President Clinton appointed him Ambassador to Korea which he was for several
414 years.

415

416 Swazey: And they were all in your group?

417

418 Jonsen: They were all in the seminar. That, in a sense, was the original cradle of
419 bioethics, Childress and Hauerwas and myself in particular. We didn't pay much
420 attention to bioethical issues, we spent those two years largely reading the classics
421 in the field of philosophical and theological ethics. We were having great debates
422 in those days about the war. Paul Ramsey came up to Yale and defended the war.

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423 Joe Fletcher came several times to lecture, to preside over our seminar as well.
424 He had already published Morals in Medicine by that time and he was really pretty
425 well into the world of medical ethics. But Jim Gustafson had that quality of being
426 able to draw people out, and he had a very broad mastery of the literature in the
427 field of ethics, historically and currently. I mean he could talk critically about
428 something that was published yesterday and something that was published in the
429 Middle Ages. Almost anything that you would say he would be able to put into a
430 context. Thirdly, he was a very gentle man. He was very committed, probably the
431 most thoroughly honest man I've ever encountered. Finally, the thing that made
432 that experience very valuable was writing a dissertation with him; that's where his
433 honesty came out. He was a scrupulous reader of dissertations, and very honest,
434 and could give directions. Once he had criticized what you had done, he could
435 give directions for correction that were so helpful. I remember, for example, one
436 point that most graduate students learn painfully that everybody learns at some
437 point in time, but when I actually had him say it to me it was a huge insight. I
438 wrote the first chapter in my dissertation and I started with the first author who'd
439 ever written about it and went through serially.

440

441 Swazey: The student Rome to Roosevelt approach!

442

443 Jonsen: Yeah! That's right! So I took the first chapter to him. He called me just a day or

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444 so before Christmas; it was snowing and I went down to his office. He said, "This
445 is not a good beginning for the dissertation but it's a good beginning for your
446 thinking about the dissertation. Now all of this material that you've got here,
447 you've got to turn it around and say, 'what's the issue that you want to pull out of
448 all of this stuff?'" Then he said, and this was the thing that struck me, "Almost
449 everything you have in this chapter should be in footnotes. The text shouldn't be
450 cluttered with all this exposition." He said, "Your readers should know that you
451 know that it's all there, but that's what a footnote is for." And you go back and
452 you look at the draft and you start saying, "Oh yeah, I can scrap that." And then
453 finally you get through all that and you say, "Ah, what's left is what I want to
454 write about." What's the essential question?

455
456 Swazey: Which is not the way too many dissertations end up looking.

457
458 Jonsen: Oh no. And Jim really was helpful.

459
460 Swazey: I think mentoring is one of the most overused words in education, but do you
461 consider Jim a mentor?

462
463 Jonsen: Absolutely, yes. I think his influence on the field has been very great. He's
464 mentored a lot of its faculty, I mean a lot of its members. A lot of them at

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465 Chicago, such as Lisa Cahill and Alan Verhey. Yes, he's a mentor. It surprised
466 me and it surprised my wife, Liz, when we were doing the index to The Birth of
467 Bioethics how many times Jim's quoted in this book because he's not a
468 bioethicist, you know. And he doesn't want to be thought of that way but at
469 many, many critical points he has contributed something that's been pivotal in the
470 way in which people thought about an issue.

471

472 Swazey: After Yale, looking at your CV, your first formal teaching position in bioethics
473 was in 1972 at UCSF. What swung you into bioethics?

474

475 Jonsen: Well, that's a kind of a weird story. I tell it in The Birth of Bioethics but I enjoy
476 telling it. When I finished my dissertation at Yale I was turning it in at the Hall of
477 Graduate Studies and I met a friend of mine on the street, right in front of Mory's.
478 All the time I was at Yale I used to go up to help in a church in Guilford and this
479 fellow, Pat McKegney, and his family were members of that church. He was the
480 chief of the psychiatric liaison service at Yale New Haven Hospital. So I had
481 gotten to know the McKegney's pretty well and I used to go sailing a lot with
482 them out of Guilford. I told Pat that I had finished my dissertation almost a month
483 before I had expected to, and he said, "What are you going to do during the
484 month?" I said, "I don't know, I'll go sailing as much as I can, I guess." He said,
485 "Why don't you come down to the hospital. You're writing all this stuff about

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486 ethics, but you probably don't know what an ethical problem really looks like, Al,
487 until you've seen ours!" So I said okay. I actually delayed my return to California
488 for another month and spent two months with Dr. McKegney, following him
489 around on the psych-liaison consultation at Yale New Haven. That was my first
490 contact with any of these issues in any realistic context. I was able to actually see
491 in reality how complex the issues were that he was dealing with. He had a sense
492 that most everything he was dealing with was an ethical problem. He hadn't had
493 any formal training in ethics. So I had that experience and then I went back to San
494 Francisco. It had been fascinating but I didn't think there would be much more to
495 it than that. I started teaching; in those days you didn't have to apply for a
496 teaching job as a Jesuit, you were just assigned to teach in a Jesuit school. So I
497 was assigned to teach the required ethics course, at the University of San
498 Francisco. Within the first year or so that I was there I met the chairman of the
499 department of surgery at UCSF, whose name was J. Engleburt Dunfy. Great
500 name, Harvard man; he'd been at Harvard for many years and finally came out to
501 be chairman at UCSF. He casually asked me what I did. I said I taught ethics at
502 USF. He said, "That's excellent. We need somebody who knows some ethics."
503 He was chairman of a committee to review the brain death criteria, and said, "Do
504 you want to come to our committee meetings?" So I said, "Yes, that sounds
505 interesting." So for probably five or six months I went to this brain death
506 committee over at UCSF and got interested in a problem that I had never really

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507 known anything about. McKegney, by the way, at Yale was very interested in the
508 dialysis-suicide problem, and that was in 1967. By that time there was enough
509 data out there....

510
511 Swazey: I'm sure that must've come up on the psychiatric liaison service.

512
513 Jonsen: Yes. Yale had their dialysis service in place by that time and it was a troubling
514 question. The Birth of Bioethics cites a couple of McKegney's articles on
515 dialysis-suicide. I encountered that problem through Pat's showing me that issue
516 and then there was the brain death problem in San Francisco. Then something
517 really weird happened to me. I'd been teaching at USF for two years, I was an
518 assistant professor. I got a call from the Jesuit superior provincial, who said,
519 "You have been appointed president of the University of San Francisco." I
520 couldn't believe my ears!!

521
522 Swazey: Must be another Al Jonsen!

523
524 Jonsen: Yes! This is insane! I said, "I have no experience as an administrator, I have no
525 desire to be an administrator. In addition, this place is a mess!" He said, "We
526 have confidence in you." The old "learn on the job." It was traditional in those
527 days for Jesuits to do as they were told, so I was ordered to do it. And so in 1969

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528 I started to be a college president. It was a very revolutionary time; those were the
529 years of travail. I thought I did a pretty good job, but I thought it was stupidity at
530 the time. I was 38 years old. I think I was the youngest college president in the
531 country at that time. Pure fluke! I did that job for three years and then another
532 funny thing happened. I felt I was doing a pretty good job but some people came
533 to me from the Graduate Theological Union in Berkeley. Do you know anything
534 about that?

535

536 Swazey: Not very much.

537

538 Jonsen: A group of seminaries, both Catholic and Protestant, that were all physically
539 located in Berkeley, right by the university, had formed a union. It provided
540 training for the ministry and was going to be done under a single umbrella
541 administratively and so forth. So it was a very creative and innovative thing at a
542 time when there was a lot of hope that the ecumenical movement was going to
543 really change the face of Christianity. The chairman of the board of that place
544 came over to see me at USF and said, "Would you be interested in standing for the
545 presidency of the Graduate Theological Union?" The founding president was
546 about to retire. I reflected on it and I thought, "that's a very interesting.... It's an
547 extraordinarily innovative and very promising sort of program." It would take me
548 back, really, into the world of theology which I wanted to pursue. It would get me

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549 out of USF in a gracious way which I was feeling was a dead end. UCSF was a
550 very small-minded school. So I said yes, and they had their search and so forth,
551 and then finally they offered me the presidency. And when they made the offer
552 three of the schools, among the seven at the Graduate Theological Union,
553 informed the board that they would leave the Union if I became president. They
554 said it had nothing to do with me. It had to do with the process that the board had
555 used, there was not full and adequate consultation. Ironically, one of the schools
556 was the Jesuit School. So I found myself in a funny situation. I had resigned
557 from the presidency of USF and now I was faced with not accepting this Graduate
558 Theological Union offer. I realized fairly quickly that to go into an institution
559 that's a union of seven schools against the feeling of some of those schools would
560 be a stupid way to start.

561

562 Swazey: A no-brainer!

563

564 Jonsen: A no-brainer! So I declined. And I was out of both jobs. It was in the papers in
565 San Francisco, "Jonsen Resigns From USF." The next day, "Jonsen Offered
566 Graduate Theological Union", "Jonsen Turns Down Graduate Theological
567 Union." After all that was in the papers, Dr. Phil Lee, who was the chancellor of
568 the medical school at UCSF, called me up and said, "I see you're out of a job." I
569 said, "I am, Phil." He said, "I'm resigning as chancellor at the end of this year and

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570 I'm going to head a health policy program that we were able to get funded by the
571 Robert Wood Johnson Foundation." I guess it was one of the first, if not the first,
572 health policy programs in the United States. He said, "We've got a lot of money
573 and we'd like to have you come over and join us for a year because we think that
574 the ethical dimensions of health policy deserve attention, and we'd like you to be
575 part of this." I'd already become familiar with UCSF through the brain death
576 committee. So I said, "What an interesting offer. I won't cost you any money at
577 all because I can't take a salary." So they gave a donation to the order, something
578 like \$10,000, and I went over there for the year and got appointed visiting
579 professor at the medical school. At the end of that year the Dean, Dr. Julius
580 Krevans said that he was interested in having me stay on. He said, "We've got a
581 state-funded position that we think we can manipulate in some ways." Those
582 were the pre-search days, you didn't have to worry about a big national search. So
583 they offered me that job and I took it. I asked my Jesuit superiors if I could do it,
584 and they said yes. In the spirit of Pope John XXIII's open policies in the church, I
585 guess.

586 So I started at UCSF and I didn't know what I was going to do; there
587 wasn't any bioethics to teach in any specific way. This was 1972, I knew about
588 the Hastings Center and I knew about the Kennedy Institute. I knew about
589 Kennedy because when I was president at USF I had been a member and chairman
590 of the Board of Directors at Georgetown. It was typical in those days that Jesuit

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591 universities would have a couple of Jesuits on their boards, usually presidents of
592 other places. When I was on the Board at Georgetown, Dr. André Hellegers was
593 putting the Kennedy Center together. I was actually on the Board that voted its
594 approval, so I knew a lot about that organization. I sought some help there and I
595 had also gotten to know Dan Callahan. Dan and I are not sure where we met each
596 other first. I remember vividly talking to him on a street corner in Cambridge
597 during one of my summer schools. He was riding his bicycle. So I spent some
598 time with André Hellegers and I spent some time with Dan at Hastings talking
599 about what a teacher of ethics in a medical school ought to be doing. Everybody
600 pretty much was at sea. Hastings had just started their involvement at Columbia
601 and they were honestly uncertain about themselves, although enthusiastic.

602 André's program was just fledgling and still very much focused on some typical
603 Catholic issues, population ethics, abortion. But he had hired Warren Reich and
604 LeRoy Walters, who also was a Yale-Gustafson student. At the same time the
605 Society for Health and Human Values had come into being. So there were some
606 people out there who were beginning to talk about possibilities of teaching,
607 though it wasn't clear what was going to be taught, by any means; humanistic,
608 humane studies.... The word "bioethics" was actually in my title at UCSF.

609 During that first year and the second year I was there, I took a lot of the medical
610 school courses; I audited them. I did a dissection and taught myself a little bit
611 about it, so I got the language of medicine in my head and saw some of the issues.

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612 Swazey: That was a very wise thing to do. I remember when I was at BU and we would get
613 letters from people just getting their PhD in philosophy saying they wanted to go
614 into bioethics or medical ethics and did they need to know anything about
615 medicine? If you have to ask that question I don't even want to look at your
616 resume!

617
618 Jonsen: Stay away! It was a very useful thing for me. I got acquainted with faculty who
619 were interested in why I was there. So I got a lot of nice connections at the
620 faculty level, but perhaps the most important connection came in neonatology
621 where the neonatologist, Bill Tooley, an extremely prominent person in the field,
622 asked me to come and participate in the rounds in the nursery. He had seen the
623 "Johns Hopkins Baby" film and wanted me to talk to his course in reproductive
624 medicine after he showed that film. Bill and I became very good friends and I
625 became a regular participant in the nursery. That experience gave me a clinical
626 appreciation of the issues. I learned enough about the science, and medicine, and
627 taking care of the newborn, that I felt very comfortable discussing the issues that
628 came up. It gave me a kind of clinical respectability; people knew I was willing to
629 be there on the service. And then I did the same thing fairly rapidly in the adult
630 intensive care unit, once again fostered by the chief of that service who thought it
631 was an interesting thing to have a discussion of ethics. So I didn't go just as a
632 consultant, I really hung around a lot! I was learning an enormous amount. So

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633 those first several years, I think, established me in a way that I would never
634 enjoyed if I had come in just as somebody giving classes to the medical students.
635 I became very much a part of the life of that institution in the years I was there,
636 from 1972 to 1987. I was on the IRB from the beginning, the Chancellor asked
637 me to chair the first ethics committee, when they put it together around 1980. I
638 was elected to the Faculty Council. I was on all sorts of committees. I had a big
639 advantage too, in that I was fairly well-known in San Francisco when I came
640 there. There was name recognition, people knew who I was and that was great.

641

642 Swazey: The unemployed guy!

643

644 Jonsen: Yea, the unemployed guy! But I'd been in the papers a lot and so forth, like
645 college presidents in a small town and USF was very much an establishment
646 school in San Francisco in those days. It had a great basketball team, in its day.
647 Bill Russell was a USF student. I had, at one point in my career as president,
648 abolished the football team which gave me a lot of publicity.

649

650 Swazey: Probably negative.

651

652 Jonsen: Yes, it was! People were saying they would never give this school a penny again,
653 and they had never given a penny before! So that was an advantage when I

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654 arrived at UCSF, which generally would be a forbidding place for a stranger like
655 me to come in to.

656

657 Swazey: Did you wear a collar?

658

659 Jonsen: No, I didn't. I got permission not to. Those were the days when clerical mufti
660 was becoming more common but I clearly felt that I had to distance myself from
661 clerical identity. I remained an active Catholic priest until 1976.

662

663 Swazey: Were people at UCSF aware that you were a Jesuit?

664

665 Jonsen: Yes, most were. It generally didn't seem to be particularly bothersome to
666 anybody. It had to be fairly clear that I wasn't there as a chaplain because once in
667 a while Catholics would come to me and say, "Would you perform my wedding?"
668 Or somebody would come in and inquire about the possibility of divorce and that
669 kind of thing. I just said, "wrong office. There is a Catholic chaplain here, go see
670 Father Burns and he can help you." But I gradually became emotionally distanced
671 from the church. There was a fairly strong reason why that happened and that is,
672 as I've told you, that my career was intended to be one in the field of moral
673 theology. During the years that I was at USF there were very strong papal
674 pronouncements against contraception, and I felt that I couldn't be a teacher of

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675 Catholic moral theology, given that position. There was a time when there was
676 enough flexibility in the Catholic position that a clever moral theologian could
677 wiggle around, but the papal statements in 1967 or 1968, whatever it was, really
678 closed those doors. And to be a teacher of Catholic moral theology with that kind
679 of restriction, I thought was unconscionable. There was some relief when I
680 moved to the presidency because I wouldn't have to teach. Also Catholic position
681 on abortion was unacceptable to me. I thought it was untrue to its own historical
682 roots. Since two main issues were ones that I didn't feel very comfortable with,
683 going over to UCSF was great. I didn't have to worry about that at all. I could
684 begin to explore the possibility of teaching ethics, in a secular setting and to
685 people who were not philosophy students. That was the challenge that I
686 immediately recognized: if you're going to teach medical ethics you have to create
687 something new and you have to attempt to make it, in some way, related to what
688 ethics has been traditionally thought to be in our culture. It must respect moral
689 philosophy and moral theology, and public morality, those kinds of general public
690 beliefs that float around, but you can't make it a metaethics course. When I
691 started at UCSF, there were a few textbooks around. There was Joe Fletcher's
692 book which I tried to use in the first year for the medical students' elective class.
693 It flopped completely because by that time most of the issues that he was
694 struggling with such as abortion, contraception and artificial insemination were
695 taken for granted. I found that The Principles of Bioethics didn't work because it

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696 was much too philosophical. Gorovitz's book didn't work because they couldn't
697 see the relationship between medicine and reading two pages of Emmanuel Kant.
698 So we had to create medical ethics from the beginning as a new thing.

699

700 Swazey: When you're talking about this period in your work you've been using a term
701 "medical ethics." And when you said "bioethics" you've almost corrected
702 yourself and said "medical ethics." What distinction are you making?

703

704 Jonsen: Well, I guess I don't make a terribly formal distinction between the two, but I
705 think there is an historical distinction. The historical distinction is the shift that
706 begins to take place in the late fifties and early sixties when questions of the
707 appropriate use of technology and science begin to arise. As distinguished from
708 what I call in the book "the long tradition" which was primarily doctors' ethics.
709 The behavior of doctors toward their patients rather than an exploration of the
710 justification for decisions. So I'm willing to call the latter bioethics and basically
711 say the tradition prior to the 1950's is medical ethics. But in the context that I'm
712 talking about at UCSF, I think we used medical ethics because it was still current
713 language and it seemed appropriate to the setting in which we were.

714

715 Swazey: Actually I called my seminars at BU Medical School medical ethics too. That was
716 in the early 1970's and I'm not sure that bioethics would have meant anything.

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717 Jonsen: Also the word “bioethics” in San Francisco in the 1960's and 1970's was
718 immediately associated with all sorts of kooky stuff. You know, macrobiotics and
719 biofeedback and all that stuff. So although I had the title, Professor of Bioethics,
720 that was because André Hellegers thought I should. The dean asked me whether I
721 wanted to be called Professor of Medical Ethics? I went and also talked to Dr.
722 Otto Guttentag and Dr. Chauncey Leake two famous names in medical ethics who
723 were at UCSF. I talked to them about what I ought to be called. Both of them
724 were wonderful, very gracious. They didn't think that I should be called Professor
725 of Medical Ethics because they thought that was physician's language. It should
726 be a physician who did medical ethics. It should be exclusively with physician
727 behavior. Both of them said there were all these new questions and a new term
728 was advisable. It was André, actually, who thought it was time to use the term
729 “bioethics” in that setting. Those two old timers, Guttentag and Leake were really
730 marvelous.

731
732 Swazey: They did some really important things.

733
734 Jonsen: Guttentag was very important in the human experimentation issues.

735
736 Swazey: Have you ever read The History of the Society for Health and Human Values?

737

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738 Jonsen: Yes.

739

740 Swazey: To me it's fascinating looking at the work they were doing in the very early fifties.
741 The United Ministries pushing for medical education, task forces on human
742 experimentation long before it got to be a highly visible set of issues.

743

744 Jonsen: They really did some remarkable things.

745

746 Swazey: You certainly are a leading representative of bioethics going to Washington and
747 bioethics entering into the policy arena. Can you talk a little bit about what got
748 you into the Washington orbit? I guess that started in 1970 when you were
749 appointed to the Artificial Heart Assessment Panel, and how that came about.

750

751 Jonsen: Yes, that was my first involvement. I was still president at USF when that
752 occurred. I don't know, to this day, how my name surfaced at the National Heart,
753 Lung and Blood Institute. I have two possible explanations. One was that André
754 Hellegers may have been the source of that nomination because, he knew Dr. Ted
755 Cooper, who was the Director of the Institute. Another possibility is that Dan
756 Callahan suggested me. When I asked Dan; he said he can't remember whether
757 he did or didn't. That appointment came out of the blue. It was just at the time
758 that I was transitioning out of USF, but I was still president then. So that was the

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759 beginning. It was a very interesting experience because I think it was the first
760 time the government had ever attempted anything quite like that. We were
761 inventing something out of whole cloth. The process was limited by the fact that
762 the panel was given a very restricted charge. I learned then that when you start
763 talking about ethics and government things, you talk about ethics the way they
764 want you to talk about ethics. There wasn't much that really surfaced as an ethical
765 problem with the exception of the problem that had been originated by the dialysis
766 issue; that is the selection question. I struggled to make everything into ethics. It
767 was the selection issue that basically got the treatment. Well, there were actually
768 two issues; there also was the experimentation question of how you move from
769 animals to humans and what steps you take. Jay Katz however was on the
770 committee, which was a great thing for me too because that's where I became a
771 good friend of Jay's. He became the experimentation expert. I tell in The Birth of
772 Bioethics a little story that I think is very illustrative of the problem of bioethics at
773 that time. I was acquainted with the selection issue because of the dialysis
774 experience and I had read all that literature. We went around debating about
775 whether there ought to be a lottery or selection criteria, and so forth. Clark
776 Havighurst was on the committee. He is a lawyer at Duke, a very, bright guy,
777 very well-read. He read Rawls' Theory of Justice, which I hadn't read, and he
778 came to a meeting with a copy and said to me, "Jonsen, have you read this book?"
779 I was ashamed because I hadn't read a book that was in my field. He said, "We

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780 ought to underpin our whole report by using this theory that this guy espouses in
781 this book.” So I went home and read the damn thing.

782

783 Swazey: It’s a long night’s read!

784

785 Jonsen: It sure is! I had a very hard time figuring out how it might be applicable to what
786 we were dealing with. It seemed to me an absolutely gorgeous exposition of
787 ethical theory. I was very much impressed with it, but I hadn’t a clue as to how to
788 use it. I think that’s a very revealing story about bioethics: if you go in with
789 ethical theory even in its most impressive forms, drawing that theory down to
790 application, to policy or to practice, is an extraordinarily difficult translation. I
791 didn’t know how to do that and I still don’t know how to do it. Norman Daniels
792 has been much more successful in using Rawls’ theory in his general treatment of
793 allocation of resources. But I think that it’s probably a generalization that ethical
794 theory has never really been very important in bioethics.

795

796 Swazey: I want to come back to that point too. Were you on the Artificial Heart
797 Assessment Panel as a philosopher or a theologian? Did they make a distinction?

798

799 Jonsen: As an Ethicist. By the time that Panel came to an end I was actually at UCSF, but
800 I think I’m still an “SJ” on the panel list; it says “Reverend”.

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801 Swazey: Was it that experience that then led you into the National Commission?

802

803 Jonsen: Yes, I guess it was. There were relatively few of us who were card-carrying
804 ethicists! The National Commission came about in a somewhat different way.
805 Let's see, we're talking now in 1973, the Commission actually had its first
806 meetings in 1974. By that time I had been in Washington as a Fellow at the
807 National Library of Medicine for a semester. I did that after a couple of semesters
808 at UCSF. I thought it would be a good thing to do some concentrated study, so I
809 went to the National Library of Medicine, which gave me an opportunity to spend
810 more time at the fledgling Kennedy Institute. And I also went up to Hastings
811 every couple of weeks, at Dan's invitation, to talk about bioethics and policy. We
812 had a little seminar. I took the train up to Hastings. So that was an opportunity to
813 get to know the Hastings people, Callahan and Veatch, in particular. I think that
814 what happened in the appointment process was this: I know, as a moral certainty,
815 that André Hellegers was a very significant figure in having that National
816 Commission put together, having the members appointed. You'll find an amusing
817 story in the book about the initial steps which I won't go into here, but André was
818 in it right from the beginning with the Shrivvers and then with Ted Kennedy. I
819 think André did pick me for that nomination because he wanted to avoid charges
820 of nepotism with The Kennedy Institute; the first thought probably was somebody
821 from the Kennedy Institute, either LeRoy Walters, or Warren Reich, or Dick

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822 McCormick if he was there. I think Dick McCormick was there at that time, but
823 André said, “No, don’t have any Kennedy Institute people because we don’t want
824 to have nepotism.” The consequence of that was...don’t take anybody from
825 Hastings either. So he indirectly vetoed Hastings people, and I showed up as the
826 neutral party. I was a pretty good choice for the Commission because I had a lot
827 of the characteristics for a government appointment. I was a Catholic theologian
828 but I was not teaching in a Catholic institution, I was in a state institution. That
829 was good. So I was kind of the Catholic, but I wasn’t the Catholic. I’d been
830 educated in ethics, both inside and outside of Catholicism. I was a Yale graduate
831 and so forth, and that was good because you were kind of a safe Catholic, not an
832 ideological Catholic. I used to joke because I was a Catholic but I had a Jewish
833 grandfather.

834
835 Swazey: That’s fascinating, because I’ve often wondered as you look at those
836 Commissions, where was Hastings and where was Kennedy?

837
838 Jonsen: Hastings didn’t get in at all. Kennedy got in indirectly because Karen Lebacqz
839 had been a Kennedy Fellow at Harvard, but that was pretty remote. Karen was
840 one of the few early people in the field; I guess she was there the first year the
841 Kennedy’s founded the Harvard Fellowships.

842

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843 Swazey: And I gathered that was pretty much, “We have money for you, do your thing.” It
844 was certainly not a bioethics program.

845

846 Jonsen: Yes, there was very little structure to it.

847

848 Swazey: That’s when George Annas got his MPH, as a Kennedy Fellow.

849

850 Jonsen: Did he? I didn’t know he was a Kennedy Fellow.

851

852 Swazey: Yes, he was in that first group and he said there was no “ethics” or “bioethics”.
853 So he figured it was a good chance to get his MPH.

854

855 Jonsen: It was Bill Curran and Arthur Dyck and I guess Stan Reiser was part of that too, as
856 the kind of faculty group. So Hastings was not a part of that Commission,
857 indirectly or directly. But Bob Veatch had a big advisory role in the formation of
858 that Commission stemming from his advisory role to the Kennedy hearings. So
859 Hastings was certainly known to the Kennedy group, to the Senator’s office,
860 because at those hearings Dan Callahan testified several times, Will Gaylin
861 testified, and Bob Veatch was an advisor to the Kennedy staff. So Hastings was
862 certainly known but they didn’t have a direct input into the Commission. It may
863 be that Dan was reluctant to get too close to government stuff.

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864 Swazey: There was a lot of debate, I remember because I was in the early group of Fellows,
865 as to whether Hastings should get involved in policy, whether they should go to
866 Washington. There was a lot of unease about it, particularly I think about
867 connections with the Kennedys.

868
869 Jonsen: I think that would be a good question to explore with Dan because I had that
870 feeling too. If they did come to him he might have been reluctant to do it because
871 he is very sensitive to getting captured by anything; that's why he didn't want to
872 get involved with the universities in the beginning. So there were two ethicists on
873 that Commission, Karen and me, but both of us were theological which is an
874 interesting thing too.

875
876 Swazey: What were your expectations, if you can go back that far in time, about what the
877 Commission was going to be able to accomplish? What did you see its role as?

878
879 Jonsen: Well, that's a good question. It goes back to what I said about the artificial heart:
880 when you take on these tasks you are given a mandate. So, in a sense, you never
881 ask, "What are we going to accomplish?" Because we are going to accomplish
882 what we're told to accomplish. There is a very complete list and it's always in
883 front of you, and the executive director is kind of ticking off each thing. So
884 there's almost no time to be really reflective about what this Commission really

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885 ought to be doing because you are told what you ought to do. Secondly, it was
886 again one of these learning experiences. What does ethics have to do with these
887 things? How does it fit in? We knew the history of things, we knew the
888 statements. At least I had read all the literature and the Daedalus essays and The
889 American Academy of Arts and Sciences proceedings and so forth, which were
890 really influential in my thinking, particularly Jonas' essay.

891

892 Swazey: I hope people are still reading that, younger people.

893

894 Jonsen: I hope so too. It's a classic. Of course, we also had Jay Katz' big book, which
895 was given to the Commission at the very beginning. So the question was, what
896 are we to accomplish in a broader sense than just going through the mandates? I
897 guess I probably thought then what I think now, that it's this task of giving shape
898 to the discourse that is the principal role that an ethicist plays in these kinds of
899 discussions. I thought Karen Lebacqz did that very well. I admired Karen's
900 ability to give shape to a discussion, and I think I do that fairly well too because
901 ethics discussions tend to go round and round and round. To kind of get it off the
902 circle and moving in a certain direction and doing that, not the way a good
903 chairman does with a discussion, but saying, "When we're talking ethics, here's
904 the significant thing that we've got to get to." That oversimplifies it, but you can
905 talk about the conditions under which people are asked to volunteer when they are

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906 patients. You can talk about that at great length, but you can focus on ethics if
907 you say in the midst of what is largely a phenomenological or sociological
908 description, “What does autonomy mean in this kind of a setting?” There is an
909 essay that John Fletcher wrote very early on. Actually it was his dissertation at
910 Union Theological. He went to NIH and studied informed consent in the context
911 of seeing people actually being asked, and says, “What does autonomy mean
912 here?” And so I think that the ethicist comes in with ideas like autonomy in their
913 head and listens to a discussion that can be very empirical and sociological and
914 says, “Well, if we’re going to make an ethics discussion out of this, let’s see what
915 the features of this concept of autonomy are that make sense in this sort of a
916 setting, or do they make sense at all?” I think that Karen and I did that a lot in the
917 Commission. For The Birth of Bioethics I did go back and read through much of
918 the transcripts. It astonished me how inarticulate people are when you think
919 you’re being articulate!

920
921 Swazey: Oh yes. I’ve gone back and looked at the Research Integrity Commission
922 transcripts and said, “Oh, Lord!”

923
924 Jonsen: It’s amazing, isn’t it? But I think that really was what was done and I think that
925 the height of that was in the formation of The Belmont Report.

926

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927 Swazey: Talk to me a little bit about the creation of The Belmont Report.

928

929 Jonsen: Again, there was a mandate in the Congressional legislation for the Commission
930 to...what was the word? Not to develop the ethical principles governing
931 research....

932

933 Swazey: To define them or articulate them or something.

934

935 Jonsen: I forget the exact language. So the first thing the Commission did was to
936 commission some philosophers and theologians to write about ethical principles
937 and what it means to develop them, or define them, or whatever it is. It's in the
938 book there. So we had Alasdair MacIntyre, and Jim Childress, and LeRoy
939 Walters, and Tris Engelhardt, and Kurt Baier write essays on the concept of
940 ethical principles. In itself that is a very interesting exercise for several reasons.
941 First, one of the important landmarks in the development of bioethics was the
942 commissioning of these and other papers that the Commission got philosophers to
943 write, because it began to draw them into a field that they had not been familiar
944 with. It's also interesting to think of a Commission sitting down and saying to a
945 bunch of philosophers, "Tell us what an ethical principle is." We got very
946 different views from all of those people because there wasn't any consensus of
947 any sort. There wasn't any ethics out there, in the way in which there's a

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948 mathematics out there, that we could just latch onto, but we got a number of
949 different viewpoints about ethical principles; some of them quite original. There's
950 not a lot of discussion of principles in ethics up to that point, believe it or not. So
951 we read those papers and then the plan was made at a certain period, I don't
952 remember how long it was, to have a retreat to discuss the ethical principles. We
953 had these papers in hand, a good number of them, from our consultants. We had
954 some general discussions about what we thought ought to go into this statement of
955 principles. Naturally we knew that there were the codes that had already been
956 created at Helsinki and Nuremberg. We felt that we ought to go beyond that and
957 we ought to try to create a document which did give some philosophical
958 grounding to the kinds of things that were said in the codes. And of course, we
959 also were aware that the big cases, as it were, that were around at the time, like
960 Tuskegee and Willowbrook, set a certain direction in which our thinking was
961 likely to go. So we had the meeting at Belmont House, which is a Smithsonian
962 Institution Retreat. We broke up into some subgroups together with our
963 consultants to talk about the various aspects of the document because, in
964 accordance with what was in the legislation, there was discussion of principles
965 which were to deal with informed consent and risk-benefit. Everybody came back
966 and gave a report. Karen Lebacqz was the chairperson for the committee on
967 principles, and that committee came back with, I think, seven or eight principles.

968

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969 Swazey: You weren't on that committee?

970

971 Jonsen: No, I think I was on risk-benefit. There was quite a vigorous discussion about
972 how many principles there ought to be. And as I say in the book, it was actually
973 Joe Brady, a behavioral psychologist from John Hopkins who suggested three
974 principles, simply because he said that seven wasn't very aesthetic and he thought
975 there were too many and we ought to have a parsimony of principles. I agreed
976 with him that we ought to be working toward a much more concise statement. We
977 thought several of the principles that were on the list from the committee could be
978 reduced to one. So that was the substance of the discussion about how many
979 principles, and that was the point at which autonomy or respect for persons,
980 beneficence and nonmaleficence and justice were sorted out. That was very much
981 in conformity with two papers from two of the consultants: Tris Engelhardt's
982 paper and a paper that Tom Beauchamp had contributed on justice. Those papers
983 had a lot of effect on the thinking of the commissioners. Then there's a fairly long
984 period of time after Belmont when there were drafts going back and forth and
985 back and forth. There were not substantive discussions at the meetings but a lot of
986 drafting and redrafting that was submitted to the Commission. By the way, it is
987 really the case that the Commission was commissioner-driven, as I think that Brad
988 Gray has subsequently said. That is, the commissioners did most of the writing;
989 we wrote it in pieces and we shared it and argued about it rather than having staff

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990 do the substantial drafting, which happened in the President's Commission. Then
991 there was a meeting of which there is no record, for reasons I have no way of
992 knowing. There was a meeting at my house in San Francisco. It was Michael
993 Yesley, Stephen Toulmin, and Karen Lebacqz, and Joe Brady, and myself, I think
994 that was the group. We were charged with doing a final draft, and we spent two
995 days at my place and worked our way through all the text that we had and argued
996 out the arguments that we wanted to have in this document, had a general
997 consensus that it ought to be very brief, and so forth. I typed it. I sat there and
998 typed language as people were talking. This was in a room that was on the roof of
999 our apartment, which was my study, with a wonderful view of the city. We
1000 commonly called that room the Belvedere so my claim is that it's "The Belvedere
1001 Report", you know. But we really substantially shaped it into the form that it has
1002 today. It went back to the Commission, had some more changes that were
1003 relatively minor, then it was given to Tom Beauchamp to redact it. He was, by
1004 that time, the full-time consultant in the position that Stephen Toulmin had at the
1005 Commission's beginning. Tom gives himself, I think, a much larger role in the
1006 creation of that report than I remember him having. I don't think he was really a
1007 participant until the very end when he was to do the final wording and shaping of
1008 it. But I don't think he was a substantial contributor although his paper for the
1009 Commission on justice contributed some ideas. Tom has consistently made it
1010 appear that The Belmont Report was something that came out of his mind

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1011 together with Jim Childress because they were contemporaneously working on the
1012 book with those principles. But I don't think that's true. "Respect for persons,"
1013 the first principle, as I remember it, got its wording largely because of my favoring
1014 that language in a book that I had recently read. A relatively recent book on
1015 Kant's philosophy called Respect for Persons by Robin Downey. I liked the
1016 language and Karen liked that language too. I think Tris Engelhardt used that in
1017 his essay. So we chose "respect for persons" rather than "autonomy."

1018 The key feature of that report, in my mind, was that it linked each
1019 principle with a practice, so where there is discussion of "respect for persons" in
1020 kind of a broad, moralist, philosophical way, then it says, "informed consent is the
1021 practice that manifests respect for persons. Beneficence and nonmaleficence are
1022 the principles which lie behind risk-benefit assessment. And justice is the set of
1023 principles that lie behind the allocation of benefits in research." There were
1024 people like Don Seldin on the Commission who wanted this to be a genuine
1025 philosophical treatise. I didn't think that was the right way to go. We prevailed on
1026 that; most of the commissioners felt that it ought to be brief, only modestly
1027 philosophical. And that's been a weakness, not in the document because I think
1028 the document has served its purposes very well, but it's been a general weakness
1029 in reference to that document as setting out principles because the principles are
1030 not very well set out. There are rough definitions given and some very modest
1031 support for the importance of those principles in the document itself. That's

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1032 where Beauchamp and Childress actually improved the situation by taking
1033 principles that are at least analogous ones because they wanted to break out four.
1034 Under “respect for persons” we also put protection of those deemed mentally
1035 incompetent. They wanted to break that out and put it in nonmaleficence, so they
1036 did some shifting around. But they began to do what the document doesn’t do,
1037 that is to put those principles into a context of philosophical argumentation and, to
1038 some extent, into a historical context of philosophical thought. Engelhardt, in his
1039 original paper for the Commission, had really taken the Kantian view in “Respect
1040 for Persons” and based his thinking on that. By the time you get to Beauchamp
1041 and Childress they’ve said, “There are Kantian roots to this and then there are
1042 Millsian roots to this.” And of course those two roots are growing in very
1043 different gardens. There’s been a mix up ever since about what’s being done with
1044 that principle at the theoretical level. At the practical level it doesn’t make that
1045 much difference. So Belmont really came out, I think, as a document that was
1046 responsive to the mandate from the Congress. It was intended to be brief, and it
1047 was intended to link some concepts and theoretical points to some practical points
1048 that could be turned into behavior on the part of those responsible for research. I
1049 was very happy with it, although as I go back and look at it now I find it rather
1050 naive.

1051

1052 Swazey: Well, I think that’s because there’s been so much water under the dam and it’s

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1053 easy to forget that it was in many ways a path-breaking statement when it came
1054 out. And it certainly has to have been the first time that Congress asked anybody
1055 to define ethical principles in any legislative mandate. It's pretty bizarre. I'm not
1056 sure it's happened since.

1057

1058 Jonsen: I say that in the book; it's amazing. I think that Charlie McCarthy was probably
1059 the one who actually wrote that legislative language.

1060

1061 Swazey: I'll have to ask Charlie.

1062

1063 Jonsen: Ask him that. But you're quite right, it's a first on stating ethical principles.
1064 And of course, everybody recognizes that that little document had an enormous
1065 effect on the creation of the discipline because it gave a set of ideas that were
1066 fairly succinct around which people could begin to think. This is a more subtle
1067 point, but maybe one might say that the fact that we put "respect for persons" first
1068 and "beneficence" second is a manifestation of this general shift between medical
1069 ethics and bioethics that moves from a paternalistic beneficence point of view to
1070 an autonomy patients' rights point of view. Although there is another way to
1071 interpret that too, and that is that it does reflect the historical circumstances of
1072 Nuremberg where the consent of the subject is the first principle. Also the
1073 document clearly reflects the Jonas view on research; I mean, one can find it there

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1074 if one knows what Jonas said.

1075

1076 Swazey: Do students still read Jonas's essay in the Daedalus book? Is that something you
1077 assign?

1078

1079 Jonsen: No. We will if we get our NIH grant to create a course on research ethics. They
1080 certainly will read it because for me that's the heart and soul of research ethics. I
1081 suppose that we would go at it differently if we were sitting down again to reflect
1082 on this. We'd go at it with the current problematic in mind. We were going at it
1083 with the problematics of Willowbrook, and Tuskegee, and Auschwitz in mind and
1084 with the history of abuses. If we had known about the radiation research that
1085 would've even pushed it further but we didn't know that...didn't know a thing
1086 about it.

1087

1088 Swazey: That's another fascinating chapter. Sort of like Tuskegee...years of silence.

1089

1090 Jonsen: We should've known about it! We should've been informed by DOD, but we
1091 never were. And so I think we would probably be much more subtle about the
1092 meaning of research than we were then. In terms of the meaning of research, we
1093 depended a lot on Bob Levine's essays for the Commission, which painfully
1094 worked out the idea of what research is in distinction from practice. We were

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1095 convinced that the primary feature of research was the design of a protocol which
1096 essentially revolved around a null hypothesis. And we were clearly living in an
1097 era where scientific research was insulated from a whole lot of other influences.
1098 That is, scientific research was done by scientists within a relatively quiet world.
1099 The NIH had made it more public by putting so much money in it. But as I say in
1100 the book, medicine began to call attention into itself by vaunting all of its
1101 miracles. So the climate of research in 1971 was still a fairly quiet one, with these
1102 occasional eruptions of scandal. But now it's a public enterprise, and that
1103 probably in large part happened because of the AIDS issue. AIDS certainly had a
1104 big influence on it. But the idea that somebody would know what research was,
1105 and how it was carried out and so forth, beyond that little quiet world was
1106 unthinkable. And now that's not the case. What we see now is that every
1107 development from initial laboratory studies on, particularly in areas that are
1108 matters of public attention, seem to be known about. They begin to acquire
1109 promise at the very earliest stages.

1110

1111 Swazey: A therapeutic misconception.

1112 Jonsen: Yes, very much so! That gets out and it's much more widely known to larger
1113 communities than it was in that quiet little scientific world of the early 1970's. So
1114 now it is much more difficult to distinguish research from a whole lot of other
1115 ideas that get picked up, it's scientific enhancement or saving of life...all of that.

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1116 You never thought about research saving life until somebody was trying to get a
1117 bill passed in Congress for the NIH for the disease of the month. But the research
1118 itself wasn't life saving. Now we think of the very earliest evidences that are
1119 coming out of a study as being "life saving." So I think we'd go at it very
1120 differently. My guess is that the idea of justice would go way up to the front and
1121 maybe even trump autonomy, because I think what the contention here is, to what
1122 extent do these new things move out into practice in a world which is already
1123 constrained in its health care resources? Can we afford as a nation to produce all
1124 of this new stuff at a time when there is so much difficulty in access to the
1125 common, ordinary, already-out-there stuff? It's in that context that I think that the
1126 autonomy question has got to be viewed. Autonomy now becomes settled within
1127 this larger question of allocation of resources. The justice part of Belmont is a
1128 pretty tiny little conception of the fact that you shouldn't do all your research on
1129 poor people. That's about all it says. But I think a revised, revisited Belmont
1130 would have a much larger place for justice, which has a whole set of interesting
1131 ramifications.

1132

1133 Swazey: In that context, have rights now become my right to have access to research,
1134 whatever drugs, procedures?

1135

1136 Jonsen: No, I don't think so. If you start with justice you take a tack which American

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1137 philosophers were not taking back in those days. We were thinking about rights
1138 as an independent concept in ethics. Basically it was my right against your right.
1139 So we're two people who each have a claim to this cup of coffee: I have a right to
1140 it because I bought it, and you have a right to it because you need coffee to stay
1141 awake. And we argue about whether your need trumps mine. That was a weird
1142 view of rights but it prevailed for a long time. I think today, at least, philosophers
1143 are much smarter about rights. That is, that rights are essentially the points within
1144 a network of social relationships. And they establish places within that
1145 relationship which may have certain kinds of absoluteness to them if you make
1146 arguments strong enough. But it's not just me versus you. It now says my right,
1147 relative to my cup of coffee, has a lot to do with the social institution within
1148 which people can buy coffee and the social institution of giving, and lending, and
1149 borrowing. So I think that a discussion of research rights, rights to be a
1150 participant in research in the old view of "I need it, therefore I must be allowed
1151 in," would be viewed very differently within a context of justice. The best
1152 example that I know from another experience has to do with bone marrow
1153 transplant for breast cancer after high dose chemotherapy. A very investigational
1154 procedure, five years ago...a very investigational procedure. But as soon as it gets
1155 reported people are demanding its use. This is not just a research question but an
1156 allocation question because it was a question of whether the insurance company
1157 was going to pay for it or not, but basically it's the same issue. People came in

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1158 saying, "I don't care whether you can tell me if this is efficacious or not with your
1159 data, that's not relevant to me. This is my last chance, therefore, I have a right to
1160 it." Well, taken alone in itself you say, "As a matter of compassion one might
1161 respond to that." But if you take the question of justice in the larger view of the
1162 availability of resources within a health plan, "Can we afford to allow people, in
1163 principle, access to procedures whose validity we know nothing about, or know
1164 little about?" And what that needed was, and in principle is possible to give, a
1165 good strong theory of justice in the managed care, or the insurance world, or so
1166 forth and so on. If the insurance world weren't so distorted by greed and
1167 maleficence.

1168

1169 Swazey: Talk about ethics!

1170

1171 Jonsen: Yes. That's why I think that one of the things that would happen in a revised
1172 debate over Belmont, if autonomy or respect for persons kept its primacy of place,
1173 is that it would be very easy to build into that a right of access to research.

1174

1175 Swazey: But of course your job in the early 1970's when you were drafting Belmont was to
1176 focus on protecting human subjects, and that's very different from saying, "Our
1177 task is to think through the ethical principles involved in social justice, and is
1178 there a right to access?" That probably never even crossed your consciousness,

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1179 given the cases you were dealing with.

1180

1181 Jonsen: It never did. The only place that it ever came up was in this little minor
1182 discussion of justice where we said, "Shouldn't people be able to get
1183 compensation for injuries..." Oh, you know where it came up? That issue came
1184 up in prison research. The guys in jail saying, "You can't deprive us of the right
1185 to be research subjects."

1186

1187 Swazey: That's right, I remember that.

1188

1189 Jonsen: "That wasn't taken away from us when we were put in jail like the right to vote
1190 was. Why shouldn't we be allowed to be research subjects? We want it."

1191

1192 Swazey: "We want to give our kidneys."

1193

1194 Jonsen: Yeah, sure. And so it did come up in that kind of odd, side context of a right to be
1195 a participant. We were almost persuaded by that, you know. The prisoners report,
1196 which came to no good in the long run, essentially affirmed that, and said that the
1197 problem with research in prisons is not that prisoners can participate in research
1198 but there is so much coercion, and so much inducement from researchers but that
1199 there is so much corruption in the prisons. If you clean up the prison situation

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1200 there would be nothing wrong with prison research. Joe Califano, who was the
1201 Secretary of DHEW at the time said, "It's not my business to reform prisons." So
1202 they just stopped research in federal prisons.

1203

1204 Swazey: But as you said, it's a very compelling argument on the prisoners' part.

1205

1206 Jonsen: Yes. That was a very striking experience, the prison visits that we did. I'd never
1207 had any experience with that world before. I guess we visited six or seven prisons
1208 with big research projects. What was obvious, first of all, was that the prisoners
1209 wanted to participate in research. Secondly, that it was not particularly risky
1210 research anyway. It was fairly innocuous stuff for the most part, but the really
1211 impressive thing was that prison research essentially had been captured by the
1212 prisoners...the inmates. Essentially every research enterprise, even run at a very
1213 high level of efficiency by Merck, or by whoever was in there running it, those
1214 guys, the inmates, had grabbed it...had control over who got in and who got out.
1215 They passed it out as a favor. They'd keep guys out that they didn't want. They
1216 had total control.

1217 Swazey: Reward system.

1218

1219 Jonsen: Yes! Just like everything else in those places.

1220

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1221 Swazey: It will be very interesting to see what NBAC does in terms of the 20th anniversary
1222 of Belmont. Are you going to be talking with them about that?

1223

1224 Jonsen: That's what they asked me to talk about. I haven't talked specifically about what
1225 they want by way of the presentation. It would probably be impossible today to
1226 write so simple a document. It was as much a declaration as it was a report, you
1227 know. It's really a declaration that research does not belong to the doctors, it
1228 doesn't belong to the researchers. And it's Hans Jonas' concept that there has got
1229 to be a partnership. I think that's what the declaration was and that was needed at
1230 the time. One other point is that I think it might also be a mistake to be too
1231 radical with any sort of revision of Belmont in the light of these new
1232 circumstances, because I think the old problems still exist and are likely to
1233 continue to exist.

1234

1235 Swazey: I have continued over the years to collect cases that come up in the media. I
1236 almost have a sense that there was a quiescence in the 1980's. People weren't
1237 paying as much attention. Late 1980's to the 1990's there have been a heck of a lot
1238 of cases, a lot of them around the mentally ill.

1239

1240 Jonsen: Yes, that's a very serious issue.

1241

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1242 Swazey: That never got dealt with by Washington, for reasons you know of.

1243

1244 Jonsen: That's right. I think that the system, the IRB system and the review system and so
1245 forth, did a lot of good but it's become routinized. And I think a lot of the people
1246 on IRBs don't really know much about the background of why such bodies even
1247 exist.

1248

1249 Swazey: I think ones that do, someone like Leonard Glantz who's on the BU IRB, is
1250 basically stifled. They don't want him to open his mouth because he is going to
1251 raise issues. That's a very sad commentary. Some IRBs have become a rubber
1252 stamp.

1253

1254 Jonsen: Yes, it really needs to be revitalized, the system does. Perhaps in some different
1255 way than we presently do it.

1256

1257 Swazey: Do you think there should be a standing ethics advisory commission or board, the
1258 type of thing that Jay Katz has argued for for years?

1259 Jonsen: I do. I think the Ethics Advisory Board that DHEW had should be revived and it
1260 should be given power. I think that it could be a stimulus to improve the system.

1261

1262 Swazey: Where would you put it?

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1263 Jonsen: Well, I guess the same place that it used to be, under the Secretary; it was an
1264 advisory board to the Secretary.

1265

1266 Swazey: Not out as sort of a separate...?

1267

1268 Jonsen: No, I see this as largely having to do with the research enterprise as such and I
1269 think that the EAB is still in the law, it's still in the regulations. It expired just
1270 when the President's Commission started, so that was 1979 or 1980. There are a
1271 lot of things such a body could do, and it would have a kind of continual input
1272 into the system to keep it greased and keep it effective, much more so than just
1273 OPRR, which has very limited resources.

1274

1275 Swazey: And is much too busy with animals....

1276

1277 Jonsen: Well, I guess that's right!

1278

1279 Swazey: Well, the animals have a much more vocal constituency than human subjects.

1280

1281 Jonsen: Yes!

1282

1283 Swazey: Would you see a need for a broader based ethics/bioethics advisory body of some

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1284 sort that looks at a broader range of issues than the EAB did?

1285

1286 Jonsen: My feeling generally has been that such an entity should be an occasional rather
1287 than ongoing thing. I think if there was an ethics advisory board in place relative
1288 to the research world, and maybe with a slightly broader.... In fact, Califano did
1289 give it a broader interpretation he said, "You can advise me on policy beyond
1290 research." He wanted them to advise him on tobacco policy which was a big issue
1291 in his mind. But I think to have a free-standing commission, or one like the
1292 President's Commission or, now NBAC, I think that ought to be occasional. I
1293 don't have many good reasons for that except I tend to think the more
1294 organization you set up in government and let run on and on they start doing kind
1295 of silly, extraneous things after a while...like Prosecutor Starr. They go hunting
1296 around for things; they do the original mandate and then go hunting around for
1297 things. I don't know. I'd rather see these commissions be like the royal
1298 commissions where they come into being for a special purpose, and do them and
1299 go out.

1300

1301 Swazey: Can you do any broad brush stroke characterizations and differences between the
1302 National and the President's Commissions, since you sat on both?

1303

1304 Jonsen: The one that I've already said I think was the striking difference is that the

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1305 National Commission really was a working Commission in the sense that all of us
1306 were very active participants in the writing of documents and we really, within the
1307 scope of the legislative mandate, set our agenda. Michael Yesley was very much
1308 a responder to the Commission's needs and desires. Ken Ryan really did run that
1309 Commission. Also, it had a lot of money because we really didn't have a budget,
1310 NIH had to pay our bills. So we got a lot of things done. We were able to
1311 commission a lot of material. We could have people come in from all over. The
1312 President's Commission was Alex Capron's Commission, he took over with a
1313 very firm hand and a firm sense of what he wanted to do. He had his staff in place
1314 even before the Commission was appointed. The agenda was set but with much
1315 less rigor than the previous Commission. The reason for that as you know, was
1316 that the National Commission had to make recommendations which had to be
1317 responded to in a certain period of time by the Secretary. The President's
1318 Commission didn't have that and so its reports more or less floated out. It didn't
1319 give that kind of specific directedness to the creation of the products. So Alex had
1320 a lot more to do with setting directions than existed in the previous Commission.
1321 I think that Ryan was a much more effective chair than Morris Abram was.
1322 Abram was an effective chair in the parliamentary sense, but I don't think he
1323 understood very clearly what some of the issues were and what some of the ideas
1324 were that were presented. I don't think he has any natural affinity for
1325 philosophical reasoning, which Ken rather does. He's not a philosopher but he

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1326 likes that kind of argument. And so Alex really ran that show. We wrote very
1327 little of the documents. There are some pieces of some of those documents that I
1328 think is my language, but it was essentially written by staff. So we'd get it and
1329 we'd criticize it, but when you get back a big document, once it's in place it's
1330 pretty much set. There's not a lot you can do. There are a few times when the
1331 commissioners rebelled on that point. The drafting of the "Splicing Life," I was
1332 very critical of and it did go back. Arnold Motulsky was very critical of it too,
1333 and it got a reworking. The other major rebellion of the Commission was the
1334 rebellion against the "Access to Health Care" document. I was off the
1335 Commission at the end and I didn't participate in it, but that's where the
1336 conservative Republican members who had been appointed to the Commission by
1337 Reagan completely rejected the draft report. The draft report was basically written
1338 by all these young liberal philosophers that Alex had gathered together. So they
1339 sent that one back for...I guess one might say, "a gutting."

1340
1341 Swazey: Were you on the Commission when that whole report was being discussed?

1342
1343 Jonsen: Yes, in the early phases.

1344
1345 Swazey: Because I gather from talking with Alex and others, and this opens onto a broader
1346 question, that there was some debate within the Commission as to whether access

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1347 to health care was a bioethical topic. Should the Commission be dealing with
1348 that? The larger theme that raises for Renée and me is our sense that those larger
1349 social justice issues, with the exception of some people like Norm Daniels, have
1350 been largely neglected by bioethics. First of all is that correct? Secondly, if so
1351 why?

1352

1353 Jonsen: I think it is correct and I think there are a number of reasons why. One reason has
1354 to do with the state of philosophical ethics, in which the large justice questions
1355 were not at all central, even for the people who were interested in normative
1356 ethics. Ethics in American philosophical writing of that time was largely personal
1357 behavior. It was issues of norms of personal behavior, not norms for social
1358 structure. It was Rawls that really shattered that conception and came in with a
1359 very, very dramatic thesis about the structure of ethics and the structure of society.
1360 In a sense it's obvious that the justice questions have been around ever since
1361 Plato, there is not doubt about that. But in American philosophy at that time there
1362 wasn't any interest in them at all. And so that was one reason why original
1363 bioethics, if you look at its ethics input, tended not to think in terms of social
1364 justice. Actually, the same thing is true in theology but in a funny way. The
1365 theological world had for several decades been very interested in social justice,
1366 both Protestant and Catholic. The social gospel movement within Protestantism,
1367 the influence of Reinhold Niebuhr for example, had emphasized social justice,

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1368 and then relationship to the social movements, and the union movements and so
1369 forth. The same thing was true in the Roman Catholic world. There had been
1370 several papal encyclicals on social justice. There was a big social justice
1371 movement in the United States that was very much union associated. Remember
1372 On the Waterfront? That was Father Corrigan, I think, in New York who worked
1373 with the unions, but that was true all over the country. Interestingly enough the
1374 theologians, who were so influential in the beginning of bioethics, knew about all
1375 that. But we didn't bring that at the beginning, we bought into this problem of
1376 individual behaviors because we were drawn by the problematic that was set up in
1377 those days of paternalism...the paternalism problem.

1378
1379 Swazey: Who set that up? Didn't you set that up yourselves, in part?

1380
1381 Jonsen: We didn't really set it up. We inherited it as a view of what medicine was.
1382 Certainly if you look at just the research problem, which becomes, in a sense,
1383 problem number one in temporal terms, the question of the authority of the
1384 researcher versus the autonomy of the subject set that problem up because that
1385 was the natural conception in the stories that we were living with, and in terms of
1386 the nature of research...the superiority of the researcher. I think that if one looks
1387 at some of the social commentary on medicine in the 1970's, that you and Renée
1388 know so thoroughly, they were setting that issue. Friedson told us to view

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1389 medicine that way. Illich told us that that's what medicine was. So it's something
1390 that the bioethicists found when they started work. If you look at the social
1391 criticism of medicine that was current in the culture before we even picked it up,
1392 some of Will Gaylin's early remarks are very strong in that respect, particularly
1393 with regard to psychiatry, his own field. Szasz is another figure that was being
1394 read and influential in that respect. So I think when the bioethicists come on the
1395 scene that was a very widespread view of medicine and their ideas were drawn to
1396 the paternalism problem. Veatch clearly buys that from the very beginning. I
1397 never really bought it completely but I was coopted into it too. In so doing, the
1398 social justice questions were left on the outside. We knew that there were
1399 problems with access and things of that sort but those weren't really big, looming
1400 problems. In fact, I think a lot of us, I have to admit this is true of me, thought
1401 that the access problems were fundamentally solved by the Medicaid/Medicare
1402 legislation. Once we got that working we would not have this social problem of
1403 insiders/outsideers in medicine. Our social problems would be reconstructing the
1404 inner medical world so that there were more patient rights, more patient
1405 autonomy. We weren't going to have to worry about the justice questions. So in
1406 sum I think there were two things. One was the weakness of American
1407 philosophy in discussions of social justice and the other was centrality of the
1408 paternalism question. Also, this fits exactly into that, since so many of us were
1409 working in medical schools we were confronted with this problem of patient-

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1410 physician relationship. We knew that the old medical ethics was fundamentally
1411 patient-physician relationship oriented. And we wanted the new medical ethics to
1412 be a refreshing of that old one, and the way you refresh it is you enhance the
1413 patient's autonomy. You made it into a therapeutic partnership. We were not in
1414 settings where we could criticize the social structures of medicine very strongly.
1415 Even the health policy activities that I was involved in early with Phil Lee, were
1416 not really strong criticism of the social world of the institutions of medicine. It
1417 was rather studies of how we could better cover people with insurance. How we
1418 could better distribute physicians around the country so that rural areas were
1419 served and that kind of stuff.

1420

1421 Swazey: I'm still struck though, and I accept historically everything you've said, but I think
1422 it was Paul Ramsey, who in the mid-1970's said one reason bioethics has focused
1423 so on the individual issues is because the larger macro issues of social justice were
1424 so intractable to moral reasoning. But as you said, there is such a long tradition in
1425 both Protestant and Catholic moral theology of dealing with those social justice or
1426 justice issues, and they certainly were big issues. Is that sort of an apologia or
1427 what?

1428

1429 Jonsen: I don't know. I think that Paul, in saying that, says one true thing and one false
1430 thing. I think the true thing he says is that they're intractable to moral reasoning

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1431 because all of those issues are so thoroughly involved in political and economic
1432 questions. You can abstract from that when you talk about whether people should
1433 tell lies or tell the truth, but when you talk about whether there should be free
1434 medicine I think it's true to say that is intractable to moral reasoning. You can
1435 make a theory that's great but it won't have any reflection in the world out there
1436 because of these huge interests. What is untrue in Paul's statement is the
1437 inference that there has not been a lot of good moral reasoning about social
1438 justice. Paul knew all that but he still had the heart of a Protestant Methodist
1439 preacher, you know? And for the Methodist preacher the question is
1440 righteousness...personal righteousness. Paul knew Niebuhr. I don't know what he
1441 thought about Niebuhr, but he's written about Niebuhr. He knew all those social
1442 justice questions but I think he could never get out of that Methodist pastor view.

1443

1444 Swazey: Because otherwise, without knowing that context it reads almost like a copout.

1445

1446 Jonsen: Yea.

1447

1448 Swazey: Another thing that fascinates me is the proclivity to say that the health care
1449 delivery, access, cost, etc., issues are policy and economic issues.

1450 In the few minutes left today, in terms of future leaders of bioethics, you
1451 were saying you don't know them.

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1452 Jonsen: True I don't really know them. That's kind of tragic and it's my fault, I guess. I
1453 had leadership positions in the Society for Health and Human Values and after I
1454 was president there I kind of separated myself from that group, and that's the
1455 place you usually would meet them. Very soon after that the American Bioethics
1456 Association came into being and I didn't have anything to do with that. I felt that
1457 it was a wrong-headed development. I thought that it was being unfaithful to the
1458 old institution, to the Society for Health and Human Values. So I just kind of
1459 stayed out of it. Dan Wikler, when he first was promoting it, wanted to get me
1460 involved but I stayed very distant from it. And that would have been another
1461 place where I would've come to know younger people. So the two convening
1462 places I haven't been involved with for five, seven, eight years. There are people
1463 among the group that I have been dealing with of course, and one of them is
1464 Nancy Jecker, who's on our own faculty here, who's an extraordinarily bright
1465 young person. Her fault is that she doesn't get deeply involved in the clinical
1466 realities, or in the realities of what she working on, but as a theoretical thinker she
1467 is very good. I have a lot of respect for Eric Juengst as well, at Case Western.
1468 Eric is a quiet personality but he is a good, solid, dependable thinker who really
1469 looks carefully at the issues that he's dealing with. It's hard for me to go much
1470 further. The issue comes up here in talking about who's going to be my
1471 successor. For me, the young generation is still Dan Brock, and Alan Buchanan,
1472 and Dan Wikler, and John Arras. I think John is great but he's the middle

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1473 generation. Those are all middle generation, see?

1474

1475 Swazey: They are now.

1476

1477 Jonsen: So, I don't know.

1478

1479 Swazey: A lot of people that I've asked that question to have had trouble coming up with
1480 names, and it's not because they don't know a range of people. But they've said
1481 in part that however wrongly they start doing comparisons with, for example, the
1482 young people who started Hastings, the young Bob Veatch's, etc. And they've
1483 said it's probably not fair because we're judging by what they then became. They
1484 seem to also have a sense that so much of the foundational work and thinking has
1485 been done, what role are the young people going to play?

1486

1487 Jonsen: That's true, and they move into already established situations. They teach courses
1488 where the content has been established. There obviously are certain people who
1489 are working in forefront areas. The people working in feminist theory, people like
1490 Susan Wolfe, in attempting to draw feminist theory into bioethics are plowing
1491 new ground. Similarly, people who are going to be working in the justice area but
1492 I can't tell you who they are. It's interesting to me when I pick up The Journal of
1493 Medicine and Philosophy now, just like the one that came today, that I don't know

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1494 any of the names of any of the authors. I think they may be doing interesting
1495 work, and they are perhaps better prepared than we were to contribute, but nobody
1496 stands out. I don't see them. Maybe this is a broader phenomenon, maybe there's
1497 a kind of an undifferentiated characteristic of young people in various fields. I
1498 don't know.

1499
1500 Swazey: I don't either, but I think perhaps that as a field becomes a field, or a discipline, or
1501 whatever you want to call it, it does become more routinized, and it may be harder
1502 for the real outstanding people to come up to the surface.

1503
1504 Jonsen: Yes.

1505
1506 Swazey: Sort of a depressing thought! It's hard to think of a new kind of a bioethics
1507 institute one could create, a new type. We have The Hastings Center Report and
1508 its progeny. We have all the work on principles.

1509
1510 Jonsen: There's a new movement to try to reintegrate religious thinking into bioethics.

1511
1512 Swazey: That's a major topic. I want to talk about it because that whole history is one I find
1513 very unsimple, very complicated.

1514 (END OF DISCUSSION FOR THE DAY)

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1515 Swazey: Maybe you could start out today by giving me your perspective on the role that
1516 religion and moral theology have played in the development of bioethics.

1517

1518 Jonsen: The role of moral theology, and that's the Roman Catholic term, or Christian
1519 ethics, the more commonly used term in Protestant denominations, had to do with
1520 several things. The first is somewhat speculative, and that is that the questions
1521 about the new biology and the new medicine were questions about life and death,
1522 and the meaning of life, and the control over human destiny, things of that sort.

1523 Those are, in a very general way, constant themes of religious ethics, attended to
1524 more or less throughout the traditions but always there. The Catholic church talks
1525 about what one has to do to attain salvation, the kinds of behaviors that you have
1526 to adhere to in order to be saved. That can get very picky, whether you have
1527 to go to church on Sunday, it's a mortal sin to eat meat on Friday, and those sorts
1528 of things. Behind all of that, of course, is the question of the meaning of morality,
1529 the meaning of life; those were familiar enough questions to theologians.

1530 Whereas, they were not very familiar questions to modern philosophers,
1531 particularly moral philosophers. The people working in moral philosophy had, for
1532 several decades, paid much more attention to the parsing of sentences that made
1533 moral statements. "You ought to stop at a red light" was the kind of thing they
1534 were interested in. And so it was not part of the idiom of moral philosophers, and
1535 it was not part of the formal studies of moral philosophy at all in that era. So, in a

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1536 sense, the questions appeared quite natural questions to the theologians and quite
1537 foreign questions to the philosophers. A second reason was perhaps more
1538 practical or realistic, that is the early people who got into the field came from
1539 religious ethics and were established in it: Joseph Fletcher and Paul Ramsey
1540 coming out of that tradition; Jim Gustafson coming out of that tradition--they
1541 brought to it their general perspectives. Religious philosophy also has always
1542 paid a lot of attention to behavior and to practice rather than concentrating on
1543 ideas. The idea of the good fascinated philosophers; the leading primary work of
1544 moral philosophy in this century is G.E. Moore's Principia Ethica, which is about
1545 the idea of the good. Religious ethics has been much more interested in behavior,
1546 what one ought to do, what one ought not to do. What ideals one ought to hold,
1547 how those ideals should be manifested in the form of institutions, and personal
1548 behavior and so forth. That made it congenial to questions that had to do with the
1549 practice of medicine, with the activities of science and things of that sort. I think
1550 that's why the religious ethicists got into the field early and impressed it with their
1551 way of viewing things. In fact, perhaps I can come back to this when we talk
1552 about the relative relationship of philosophy and theology. Maybe I should say it
1553 right now. The religious ethicists brought some pieces of their tradition. The
1554 Roman Catholic moral theologians, for example, such as I was, had fairly worked
1555 out pieces that fit into the new questions of bioethics and that had been around for
1556 a long, long time. That is, it has been traditional since at least the 16th century to

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1557 consider questions of appropriate medical practice. Interestingly enough,
1558 ironically enough, the Roman Catholic moral theologians always considered that
1559 in their books when they treated the fifth commandment, “Thou shalt not kill,”
1560 because the questions of medicine about life and death had to do with what
1561 physicians could do or could not do to avoid killing their patients. So the idea of
1562 ordinary and extraordinary means of care, for example, go back to the 16th century
1563 in terms of the conceptual ways of working at those things. Similarly, a lot of
1564 questions around abortion and contraception had been in the Roman Catholic
1565 moral tradition for a long time. So what Catholics could do was, in a sense,
1566 abstract lines of argumentation from those traditions that were not specifically
1567 ecclesiastical or theological. It has to be recognized, as far as Roman Catholics
1568 are concerned, that almost all of practical reasoning in Roman Catholic moral
1569 theology was based on the theory of natural law, which meant that practical
1570 reasoning was not based upon biblical interpretation, was not based upon
1571 theological doctrines, and so forth. The only way in which theology plays a really
1572 strong role in Roman Catholic moral theology in its traditional sense, which was
1573 the authority of the church to say that this particular argument of natural law
1574 reasoning is to be considered valid or invalid. The church claimed the authority as
1575 a teacher of morality to be able to adjudicate natural law reasoning. But the
1576 natural law reasoning is reasoning that Roman Catholic moral theologians would
1577 say any human being, regardless of whether they are Catholic, or Protestant, or

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1578 Buddhist, or whatever, can understand. So when the Catholics came to bioethics
1579 they brought pieces of fairly well-worked out questions into the argument and at
1580 the same time they de-theologized them when they did that. Not just because
1581 they wanted just to communicate with the wider world but because that was their
1582 tradition, to use philosophical natural reasoning in dealing with moral questions.

1583 With the Protestants it was a little different because natural law reasoning
1584 had been repudiated in the Reformation by the great reformers, although Calvin
1585 kept parts of it and respected it. But in general, there was a very strong trend in
1586 Protestant religious ethics to become much more biblically based. They of course,
1587 didn't have the strong tradition of ecclesiastical authority, but the reading of the
1588 Bible as a document of moral instruction, the preaching based upon that, gave to
1589 most Protestant thought a much more theological tone. However, in the 20th
1590 century, particularly in the post-social gospel era that I was talking about
1591 yesterday, essentially from the 1920's on, when they plunged into a practical realm
1592 of social, political, financial and economic practices in the world, like "what
1593 should labor unions be doing?," and particularly the questions surrounding the
1594 legitimacy of war, whether the church should be pacifist, they too began to make
1595 arguments about these moral questions that were much more arguments of reason
1596 rather than arguments of theological dictate. For example, the Christian pacifist
1597 arguments, were very largely biblically based, based upon New Testament texts,
1598 for example, in which Jesus appears to repudiate violence. And the anti-pacifist

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1599 arguments in the Christian church, made by people like Niebuhr, were not
1600 biblically based but reason based. And so you had an interesting similarity at the
1601 time the theologians began to get interested in bioethics. Both of them, Catholics
1602 and Protestants were coming at the issues with an appreciation of reason based
1603 argumentation, the Catholics because it had always been in their tradition, and the
1604 Protestants because it had been a relatively new discovery in their way of doing
1605 ethics.

1606 So I think it's a fallacy to say that the theologians abandoned religion, as
1607 some people have said. Stanley Hauerwas particularly, and now Tris Engelhardt,
1608 are saying that the theologians started out in this field as theologians and then they
1609 gave it up. They give different reasons for it. One is the practical reason of
1610 having to communicate with people who don't share their faith. And the cynical
1611 reason is that the early bioethicists were employed by secular schools, and
1612 therefore couldn't talk religious language. That applies to me: I'm a theologian
1613 hired by the University of California and I can't go in and preach Catholic
1614 thought. So they say, "Well, that's the reason why people like Jonsen gave up
1615 talking theology." I don't think, for the most part, the theologians of that era
1616 talked theology when it came to ethics. They talked arguments of reason. There
1617 were, at that time, several very, very interesting internal debates going on. In
1618 Roman Catholic moral theology there was a debate about the principle of double
1619 effect which was extremely far reaching. It wasn't just the application that we use

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1620 in bioethics now about whether you can give pain killing medications to people
1621 that are dying and thereby hasten their death; it was a much broader discussion
1622 about the structure of moral reasoning. Richard McCormick was a very
1623 prominent figure in that debate which actually originated among Catholic moral
1624 theologians in Europe. And so that's an argument about how you reason about
1625 moral matters that are perplexing in which both sides appear to be right or wrong,
1626 depending. In Protestant theological circles, at just about the same time, there was
1627 a big debate about norms and rules. When you make a normative statement it's
1628 always a generality or a universality such as "thou shalt not kill." When you get
1629 down to the actual moment in which a decision has to be made whether to defend
1630 oneself against an attacker, or whether to assist someone to die, how does that
1631 general rule apply to the circumstances? And so the Protestants were debating an
1632 issue about moral reasoning at the same time that the Catholics were debating a
1633 question about moral reasoning. In neither of them is the question a profoundly
1634 theological one. It is in its deep roots but for the most part it's a question of the
1635 logic of moral reasoning. To some extent in both debates they begin to touch the
1636 edges of what moral philosophy was doing at the same time, because questions of
1637 structure of moral reasoning were involved.

1638

1639 Swazey: In terms of normative ethics?

1640

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1641 Jonsen: In terms of normative ethics. I think that's also a reason why one of the earliest
1642 philosophers to get into the field got into it, namely Stephen Toulmin, because his
1643 approach to normative ethics was clearly concerned about this normative principle
1644 in relationship to actual circumstances. His early essay that had very widespread
1645 currency, "How Medicine Saved the Life of Moral Philosophy," expresses that.
1646 Then some philosophers began to drift into the field. Dan Callahan clearly is one,
1647 but it's interesting that while Dan was a philosophy major at Yale and then did his
1648 doctorate at Harvard, he also came out of a traditional Catholic family. While he
1649 has never spoken as a Catholic with doctrinal background, he was very much
1650 permeated by it as one can see in his early book on abortion. The arrival of
1651 philosophers in the field really starts a little bit later than the theologians. If one
1652 looks at the events of the 1960's when ethicists begin to pop up at medical or
1653 scientific conferences, they're mostly theologians at that point in time. Most
1654 moral philosophers, if invited to go to a conference to speak on discontinuing
1655 renal dialysis, if they were honest would probably say, "I don't really have
1656 anything to say about that." A few showed up and they did what philosophers are
1657 usually expected to do, like Abraham Kaplan of UCLA showing up at one of
1658 those conferences and making some remarks about the meaning of terms and the
1659 logic of argument, but it's mostly the theologians that appear in the 1960's. In the
1660 early 1970's the philosophers begin to appear much more frequently--Callahan
1661 very prominently, Tris Engelhardt just having finished his philosophy degree and

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1662 his medical degree, Tom Beauchamp, Danner Clouser who actually shows up at
1663 the end of the 1960's. By that time the division between theology and philosophy
1664 was pretty much wiped out because the practical questions were very, very heavily
1665 on the agenda. The ethicists were paying attention to the dimensions of the
1666 practical issues, such as the definition of death and allocation of scarce resources.
1667 You notice in the first great book in the field, in Ramsey's Patient as Person, he
1668 starts out by saying that he is writing as a Christian ethicist but there's very little
1669 theological thought expressed throughout that book. There are references to
1670 theological sources of morality, ideas of divine love and compassion, but all of the
1671 essays that make up that book are very strongly written in terms of moral
1672 reasoning. They're logical arguments, the assessment of arguments justifying one
1673 course of action or another course of action. So while it's a hard book to read and
1674 many people say, "Oh, it's so theological," it's not theological at all. It has
1675 theological terms here and there but it's really Ramsey's logical mind working at
1676 these issues. I've written in an obscure essay somewhere, actually it's in a
1677 festschrift for Jim Gustafson, that the ethics and the ethicists of the early era of
1678 bioethics were improvisers, the ethics was improvisation and the ethicists were
1679 improvisers. I try to analyze the idea of improvisation in terms of music, actually,
1680 where a pianist or a violinist in the classical concerto will take off from the
1681 themes and improvise on them and the improvisation is very largely creative
1682 within a set of general thematic presentations that have been built into the written

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1683 part of the symphony or the concerto. I think that is what bioethics was and still
1684 is, is a form of improvisation in which people came out of traditions in which
1685 there were certain sorts of themes, either the religious tradition, Protestant or
1686 Catholic, or the philosophical tradition. And by the way, the philosophical
1687 tradition was also somewhat diverse. We always think of it in terms of the logical
1688 analysis approach, but there was also, in the 1960's, the phenomenological
1689 approach and the existentialist approach, both of which were kind of minor
1690 streams in American philosophy, but still they were there. Bill Winslade, for
1691 example, who did his philosophy degree at Northwestern, did it primarily under
1692 people who were phenomenologists. That was a great center for American
1693 phenomenology. So there were those other traditions too. People coming from
1694 the world of ethics' studies in both philosophy and theology had some very
1695 general themes that their traditions gave to them, but when they came down to
1696 dealing with questions that were posed by the new medicine, the new biology,
1697 they improvised. They pulled pieces from here and from there. A number of
1698 people were equally comfortable with philosophical and theological reasoning. I
1699 told you yesterday I felt very comfortable in both idioms. Most people who came
1700 from the Roman Catholic tradition never saw philosophy as foreign from
1701 theology. There were a lot of resources about how to define ethical terms, how to
1702 make arguments about ethics, so forth and so on. They drew from all of that and
1703 improvised when it came to making arguments. So if you actually look at the

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1704 essays that were written for the National Commission, the essays written by
1705 philosophers and the essays written by theologians look pretty much the same.
1706 There's no great recourse to biblical or theological reasoning, or even to
1707 ecclesiastical authoritarianism such as it existed in the Catholic church. The
1708 arguments in those essays look pretty much the same. If you didn't know that Jim
1709 Childress was a theologian, and that Kurt Baier was a philosopher, you wouldn't
1710 be able to tell by reading those essays.

1711

1712 Swazey: Apart from the fact that both groups were, as you said, engaging in moral
1713 reasoning, does the fact that these papers were being written for a government
1714 commission, also influence the extent to which they were explicitly drawing, or
1715 not drawing, on religious perspectives? And was there a sense that they needed to
1716 be in "secular" language?

1717 Jonsen: Well, I don't know that. I think the only test of that was, did they write differently
1718 when they wrote for different sponsors? And they didn't. Jim Childress' material
1719 was published in other places, as some of the initial literature about bioethics, and
1720 it looks the same. In the Western theological tradition, with the exception of a
1721 more fundamentalist approach, I think it's almost inevitable that after some
1722 theological premises are stated, the theologians will move down to logical
1723 argumentation. There was also a big debate, largely within Protestant thought, but
1724 somewhat reflected within Catholic thought during the 1950's and 60's, about

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1725 what makes religious ethics distinct from any other ethics. There was a lot of
1726 literature poured out about that. Jim Gustafson was a major contributor to that
1727 debate. There was a group of theologians in England, for example, very much
1728 entranced by and affected by the logical positivism or the logical analysis
1729 approach that was so favored in the English universities at the time, who were
1730 writing theology in ways that they felt was compatible with the logical
1731 philosophical approach. Their question was, “what is it about theological ethics
1732 that makes it any different?” And different sorts of arguments came up. It’s the
1733 commitment of individuals, it’s the question of the recognition of an ultimate
1734 judgement on one’s actions, things of that sort. But it isn’t the content that’s very
1735 different. It’s hard to find content that’s different. On certain pieces, yes. Roman
1736 Catholic thought on contraception is probably the most idiosyncratic piece of
1737 Roman Catholic theology. Abortion not so much so, because as we know from
1738 subsequent developments, the anti-abortion arguments cut across all religious and
1739 even secular lines. It’s not as if you can say that pro-choice is all secularist and
1740 pro-life is all religious. Contraception is a different matter, and I wish I could tell
1741 you why. I don’t really know why..in any definitive way. But the argument, how
1742 does religious ethics differ from ethics done in a secular way, was a vital
1743 argument just about the time that bioethics was coming into being.

1744

1745 Swazey: I know Jim Gustafson made a statement, it may have been in his book on

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1746 Theology and Medical Ethics, that he thought theological ethics would not make a
1747 major contribution to medical ethics because the arguments and principles could
1748 be stated in philosophical secular terms, essentially just as well.

1749
1750 Jonsen: That's exactly right. That's in his Marquette lecture on medical ethics and
1751 theological ethics. That's true and that's the position that he takes. He believes
1752 that for a believer with a theologically grounded faith there will be perspectives on
1753 the meaning of life that are not shared by people who are not believers, and that
1754 there may be motivations to act in ways that non-believers do not share. But those
1755 perspectives have little to do with the substance of the arguments about the
1756 rightness or wrongness of action. You can make the same arguments
1757 theologically or philosophically.

1758
1759 Swazey: What you're saying in a nutshell, I think, is that after the great initial cohort of
1760 figures like Ramsey, Joe Fletcher, Jim Gustafson, Dick McCormick there have
1761 continued to be major figures in bioethics who have come out of a religious
1762 tradition but essentially are writing like the philosophers are, because they are
1763 doing the same types of improvisational work, and engaging in moral reasoning.

1764
1765 Jonsen: I do feel that. There's clearly now a group of younger people who come from the
1766 theological background who are vitally interested in discovering a way in which

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1767 theological argument may be more cogent in actually affecting the analysis of
1768 particular problems. Alan Verhey, who is a Gustafson student, is very concerned
1769 about that. Kevin Wildes is very interested in that; he is an Engelhardt student.
1770 They are trying to present argumentation that would make a theologically distinct
1771 form of bioethics. I haven't been particularly convinced by their approaches. But
1772 I also have to admit that I haven't read a lot of their work because for me that
1773 question is a kind of settled question.

1774

1775 Swazey: What about the Jewish traditions? I know there has been a long tradition of
1776 Orthodox Judaism dealing with these issues, but as bioethics began, it doesn't
1777 seem there was a major role of orthodox, or conservative, or reform Judaism. Is
1778 that because they were primarily writing for their religious communities?

1779

1780 Jonsen: That's my impression, that Jewish thought, which is often times fascinating and
1781 compelling, has traditionally been written for the Jewish audience. Once in a
1782 while a Jewish author like Abraham Heshel or Martin Buber caught the fancy of
1783 the wider world and had significant impact. But for the most part, the writing was
1784 within the community and that's a reasonable thing because it's a position of
1785 Jewish thought that Jewish law--you know they prefer that term to talking about
1786 Jewish ethics--that Jewish law pertains to Jewish people. There is a parallel to the
1787 natural law tradition within Judaism which suggests that there are laws that are

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1788 common to Jews and non-Jews. But that's not a really big part of it. So the work
1789 of the Jewish scholar, the Rabbi writing about ethics, is largely to speak to their
1790 own people. Secondly, rabbinic writings are a very unique idiom which is hard to
1791 translate into secular thinking. The importance of the reference to traditional
1792 authority, for example, will make the reading of an essay on some bioethical
1793 subject written by a Jewish scholar impenetrable to a non-Jewish reader. The
1794 reference to Rabbi this and Rabbi that, in particular the very close analysis of
1795 terms, of language, which has a parallel to Roman Catholic casuistry in a way, is
1796 often times done by reference to traditional meanings of words and things of that
1797 sort. It's very hard to translate that idiom. Certain people early in the bioethics
1798 world began to do that to some extent. Fred Rosen was perhaps one of the most
1799 visible of the translators between the strict rabbinic and the practical world of
1800 medical decision making. Several of the Rabbis, like Bleich and Tendler, have
1801 gotten close to doing that too. Although it's interesting, Tendler has just edited a
1802 collection of the opinions of his father-in-law who I think was the Chief Rabbi of
1803 Jerusalem where you can see Tendler's preoccupation with the properly Talmudic
1804 form of argumentation. So I think that's the reason why they stayed somewhat on
1805 the sidelines.

1806

1807 Swazey: There seems to be a florescence of Jewish medical ethics conferences now.

1808

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1809 Jonsen: Yes, I don't know why that's the case except that it may be that it's a part of this
1810 more general phenomenon of the interest among younger Jewish people in the
1811 traditions of their faith. And since the medical community in the United States
1812 has a very high percentage of Jewish members, I think that general interest in the
1813 return to the sources of Judaic belief may have a lot to do with that florescence.
1814 The San Francisco conference...I forget the name of the Rabbi who has put it on,
1815 remains very heavily, really almost exclusively, focused on Jewish issues and
1816 draws very, very largely on the Jewish medical community for its speakers rather
1817 than just the Rabbis. It's interesting that the synagogues...I went to a meeting at
1818 B'nai B'rith just a couple of weeks ago on life support that drew a big audience in
1819 which a Jewish educator, not a Rabbi, and a Jewish doctor both presented their
1820 points of view. I was astonished at the number of people in the audience.

1821
1822 Swazey: Quite apart from how you're assessing the caliber of some of the younger people
1823 trying to reintroduce theological ethics into bioethics, given the pluralism of
1824 American society do you think that is a drive that could succeed? To move more
1825 from the moral reasoning framework to the more explicitly theological
1826 dimensions.

1827
1828 Jonsen: I don't think it will succeed. I think there is one place where it might succeed and
1829 that's within fundamentalist Christianity as it becomes more intellectual. As you

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1830 know, the history of American Christian fundamentalism is a fascinating, complex
1831 one. It's main streaming itself now, and large numbers of its participants are
1832 educated and intelligent people who are interested in developing more articulated
1833 positions that are in conformity with their beliefs. And so I think that there may
1834 be a Christian bioethics created within that sphere.

1835

1836 Swazey: Do you think it would move outside of that sphere though, or would it be more
1837 confined like Jewish medical ethics has been?

1838

1839 Jonsen: I think it would remain more confined. I think it would. It's interesting that the
1840 title of the new journal that Engelhardt, Wildes, and Stanley Hauerwas put
1841 together, is Christian Bioethics and the subtitle is A Non-Ecumenical Journal.

1842

1843 Swazey: That's pretty explicit.

1844

1845 Jonsen: Yes.

1846

1847 Swazey: You've said in our conversation and certainly written that you don't think that
1848 philosophical theory has had a great role to play in bioethics. Could you expand
1849 on that a little bit?

1850

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1851 Jonsen: First of all, I don't think that there is a very clear or strong concept of theory in
1852 moral philosophy; there never has been. One can read all of Plato, or one can read
1853 all of Kant and call it theory if one wishes to do so. But the idea of what theory is
1854 supposed to do in ethics has never been very clearly articulated. John Rawls
1855 makes a very good move in the direction of articulating what theory is supposed to
1856 do. But theory means very different things to different people working in moral
1857 philosophy. I've got five or six different quotes from moral philosophers in The
1858 Birth of Bioethics that show very different approaches. So given the fact that
1859 theory has never had this very powerful conceptualization in moral philosophy, is
1860 one reason why it doesn't mean much. The most common use of the concept of
1861 theory in moral philosophy is to designate the form of reasoning which establishes
1862 the validity of moral arguments. For most of the 20th century that has meant the
1863 theories that established the validity of arguments about obligation, and for the
1864 most part that's been the debate between theories that are consequentialist and
1865 utilitarian in scope and theories that are not. There is no doubt that an enormous
1866 amount of philosophical ink has been spilled over the structure of utilitarian
1867 theory. The others, the "not" theories, the non-consequentialist or sometimes
1868 called deontological theories, are scattered all over the place. Even the favorite
1869 book of people who adhere to the "not" side, which is Ross' The Right and the
1870 Good, is not a very clearly articulated basis for deontological reasoning. The
1871 utilitarian theory has been so punctured over the years and it keeps coming back to

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1872 life, in a variety of ways, but critical analysis has just found it thoroughly
1873 unsatisfactory in many, many respects.

1874

1875 Swazey: Medicine, I think, has always been particularly congenial to a utilitarian approach.

1876

1877 Jonsen: There's no doubt that's the case but as a philosophical theory it's very weak. And
1878 yet, as I say, it keeps coming back. So that's the second reason why theory is not
1879 very important. There isn't any great agreement about what those theories are and
1880 how they ought to function. And when you read Beauchamp and Childress'
1881 Principles, they say, "Well, here are these two theories of obligation and here are
1882 the pros and here are the cons but it really doesn't make much difference."
1883 Arguing about particular cases is going to pretty much end up the same way
1884 regardless of what theory you take. Now there are points at which that's not
1885 entirely adequate. You can push arguments back to a point where you say, "Well,
1886 you've got to decide whether you're going to be utilitarian or not be a utilitarian."
1887 But again, you get into a circle because it's not entirely clear what it means to be a
1888 utilitarian. The third reason why theory has not played much of a role is that the
1889 relationship between theory and practical judgement is very unclear. That's the
1890 point that I mentioned a few moments ago in talking about that debate among the
1891 Protestant religious ethicists about deeds and rules. It's the general problem of
1892 how you move from general affirmations to particular statements of rightness and

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1893 wrongness. That was the issue that drove Stephen Toulmin and I to begin to
1894 explore casuistry, because casuistry is an attempt to deal with the rule-decision
1895 relationship. Sometimes it doesn't look like that because there is so much
1896 attention paid to particular cases. But basically it's a question of how rules apply.
1897 The application of rules to particular decisions is highly circumstantial. If you
1898 take that statement in its most radical form you're into situationism. And if you
1899 take it in a more restricted form you are into casuistry, which says the question is
1900 how do you analyze circumstances in relationship to general rules, or how do you
1901 analyze rules in relationship to particular circumstances? It occurred to many of
1902 us early on that the interesting features of bioethics were its cases; that when we
1903 talked about discontinuing life support it really came down largely, to use the title
1904 of that famous play and film, "Who's Life Is It Anyway?" or what kind of life is
1905 it? All of those are questions that are casuistic. Who is this person? What is their
1906 life at this point in time? What is it that the medical intervention can actually do
1907 for them? And a whole range of other questions like what costs are involved and
1908 so on. At that point the perception is that any theory as such is much too general
1909 in scope...much too general to deal with the kinds of questions that are of interest
1910 in bioethics. Again, that's Stephen Toulmin's "How Medicine Saved the Life of
1911 Ethics," which is an essay that he wrote when he and I were in the middle of doing
1912 the casuistry book. So I think those are three reasons why theory has not been of
1913 much interest. It's interesting there are a couple of efforts at general theories, like

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1914 Engelhardt's book and Bob Veatch's and so forth. They are interesting but I don't
1915 think they've had much impact.

1916

1917 Swazey: Probably read more by academic philosophers than...

1918

1919 Jonsen: Strangely enough, it appears that Engelhardt's book is generally read as a standard
1920 example of American bioethics by Europeans. What should you read to know
1921 what American bioethics is? You read Engelhardt. That was my impression
1922 when I interviewed a number of people in Europe, that they had read Engelhardt
1923 and they hadn't read anything else.

1924

1925 Swazey: That's kind of giving them a skewed perception....

1926

1927 Jonsen: Very much so.

1928

1929 Swazey: Does that mean from your perspective that the current raging debate about
1930 principlism and alternate theoretical constructs is not terribly relevant to doing
1931 bioethics?

1932

1933 Jonsen: I think it's relevant. Notice that the debate is not about theory and practice, it's
1934 about principles and practice. There's no way in which you can get away from

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1935 principles. You can be very cavalier about theory and ethics, I think, but you can't
1936 get away from principles because principles are always thrown into the debate by
1937 anybody arguing for one way or another. I think the debate about principles is
1938 overdone. People are finding things to argue about that I don't think are worthy of
1939 argument. But careful articulation of the principle/decision relationship is
1940 something ethicists always ought to be doing. It's going to come out differently.
1941 In Aristotle, for example, there are two quite different approaches to that problem
1942 depending on the way in which one reads the Aristotelian text. One is the kind of
1943 syllogistic reasoning, where you go from major premises stated as general
1944 principles, to particular conclusions. And the other is his argument about the
1945 perception of what is right in a particular situation. Those can be seen either as
1946 complementary or they can be seen as contradictory, or as if he's written one
1947 when he's awake and the other one when he's asleep, or one when he is sober and
1948 the other when he is drunk. So that particular debate ought to continue on in
1949 moral philosophy. Do we have ways of arguing syllogistically from principles
1950 that really function well, or do we have to rely on radical intuitions into the
1951 rightness of circumstances or cases? The principlism debate, to the extent that it's
1952 a continuation of this kind of classical internal discussion among moral
1953 philosophers, is a good thing.

1954
1955 Swazey: Where does law, American jurisprudence, fit into philosophy...moral

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1956 reasoning...in bioethics? As you know, there certainly is a spectrum from the
1957 George Annas view that bioethics is going to disappear because it's in the end just
1958 law, to broader perspectives like Alex Capron's.

1959

1960 Jonsen: Yes. Well, there are different points of view that one can take about it, but I think
1961 that I will always say that law and ethics are different. They have different
1962 objectives. They have different sources, different purposes, but the ethical
1963 decision or the ethical question in any particular case has to have reference to or
1964 take account of what the law has established or would appear to establish. In the
1965 most fundamental sense, the problem of conscientious objection is the most
1966 radical demonstration of the law-ethics relationship; it's when somebody says, "I
1967 can't obey this law in conscience." If law and ethics were the same thing that
1968 question would never come up. I think most of us repudiate legal positivism.
1969 And then the question is: Can we ethically evaluate the moral relevance of the
1970 law? The law might put you in jail but the question is: Is it good law, is it right
1971 law? So I think you always have to have a distinction between law and ethics.
1972 There's no doubt that American jurisprudence and bioethics have many
1973 interesting points in common. That has to do with the history; that is, Anglo-
1974 American jurisprudence grew up within a world of thinking where legal reasoning
1975 and ethical reasoning were very parallel, and that's historically the case. One can
1976 find that most of the forms of legal argumentation are imitations of forms of

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1977 ethical argumentation. So I think that George exaggerates. I think that bioethics
1978 and the law about bioethical issues are in an interesting conversation but it seems
1979 to me that many of the great decisions made by the courts have really paralleled or
1980 imitated ethical argumentation. That's not entirely the case because American
1981 court decisions have to follow certain sorts of rules and you have to pay attention
1982 to precedent very, very rigorously. Precedent is not a feature of moral
1983 argumentation but there are many parts of the great legal decisions that could just
1984 as easily be thought of as moral argumentation. Then there's another question
1985 too: if you construct good moral arguments about things, whether or not you ought
1986 to attempt to make those legal formulations as well. My tentative answer is,
1987 probably not.

1988
1989 Swazey: Does that bear on the role of the ethicist as an expert witness in legal cases?

1990
1991 Jonsen: Well, I don't know. I think that there's a fairly restrictive role for the ethicist in
1992 legal cases and that is to simply give testimony as to what the prevailing opinion
1993 is within the ethics community, relative to a particular issue. So that if a physician
1994 defends himself or herself in a particular action by saying, "What I did was
1995 ethical," one response to that is, "Well, whose ethics?" If he says, "My ethics,"
1996 then we don't have much to say. But if he says, "This is the ethics of the
1997 profession, or it's the prevailing ethical opinion," then an ethicist can come in and

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1998 say, “Well, it is true that if you read all the articles about withdrawing life support,
1999 you’ll find it very largely going in the direction of Dr. So and So says...” Then the
2000 court’s going to have to do what it wishes to do with that kind of opinion. It
2001 seems to me that it is, in a sense, the ethical parallel to expert opinion in medical
2002 matters. But it isn’t that the ethicist makes a judgement as to whether the legal
2003 provision, if there is one, if there is a statute, is right or wrong. I don’t think we
2004 ought to do that.

2005

2006 Swazey: That certainly, as you know, is a fairly debated topic.

2007

2008 Jonsen: Yes. I’ve got a case now that illustrates that. It’s a question of resuscitation of a
2009 newborn in which the attending physicians, at the time of birth, judged that
2010 resuscitation was not appropriate; they were unable to consult with mother and
2011 father at that point. They decided not to resuscitate, and the baby, in fact, did not
2012 die immediately and then a resuscitation was attempted quite late. I’m asked to
2013 testify on whether the initial decision not to resuscitate is in conformity with
2014 prevailing beliefs in bioethics.

2015

2016 Swazey: The major players at the bioethics table have been philosophers, religionists,
2017 lawyers, and medical professionals. What do you think accounts for the long
2018 prevailing tensions between bioethics and social sciences?

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2019 Jonsen: I think in part it comes from the majority of the traditional bioethicists not
2020 knowing anything about the social sciences. I have always thought of myself as
2021 an exception to that. I didn't mention to you the other day when I was talking
2022 about my history that I was an anthropology minor during my college days. And I
2023 did two summers of field work on the Crow Reservation, and really wanted to go
2024 into anthropology. At one point in time I was all lined up to go to Harvard for
2025 anthropology. So I read a lot of anthropology and even taught one course in
2026 anthropology when I was teaching at Loyola University.

2027
2028 Swazey: I think, though, you can say the flip side is also true, that there are not many social
2029 scientists who have any grounding in philosophy or theology.

2030
2031 Jonsen: Yes, I think it was a mutual ignorance of each side. I think, of course, that there's
2032 an ideological difference to the extent to which they do know about each other.
2033 Certain people working in ethics probably have viewed sociology and
2034 anthropology as ethically relativistic. On the other hand, people in social sciences
2035 have viewed philosophers and theologians as ethical absolutists, which was
2036 empirically absurd. So I think that there was probably this ideological difference
2037 that said, "What do we have to do with these absolutists, and what do we have to
2038 do with these relativists?," which is false because you've got as many relativists in
2039 the philosophy camp and vice versa. I think there was that relative ignorance and

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2040 the ideological perceptions about the two. And I also think, as I mentioned briefly
2041 in the book, that the really remarkable efforts to bring the social sciences into
2042 medical education that were moving ahead in the 1950's and 1960's were
2043 overshadowed by the immediate popularity of the ethics. That was, I think, in part
2044 due to the fact that the doctors recognized that the ethics was something that was
2045 already within their tradition anyway and that it had something to do with practice
2046 that was fairly direct. Whereas, all the sociologists and anthropologists were
2047 doing was telling them what they were doing, and they weren't interested in that.
2048 They didn't see that as shedding any light, which of course is stupid. People like
2049 Anselm Strauss, for example, whom I knew very well, I think was deeply hurt by
2050 the way in which his role at UCSF was marginalized.

2051
2052 Swazey: It's been a fascinating sort of contemporary historical sequence in medical
2053 education, because all of it's been done in the name of "humanizing" medicine by
2054 various disciplinary sort of parachutes.

2055
2056 Jonsen: Yes.

2057
2058 Swazey: Is another possible factor that a lot of the schools of moral reasoning in bioethics
2059 didn't see a need for empirical information? It has been at a level of abstraction
2060 where empirical data didn't much matter. Alex has made the same argument

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2061 about a lot of policy: that it's made in the absence of, or despite empirical data,
2062 which is seen as sort of irrelevant.

2063

2064 Jonsen: I'd say there was something else to it than just a lack of relevance. I think it was
2065 much more a question of the philosophers and theologians thinking that they knew
2066 what the facts were. They didn't need anybody to tell them more. I think there
2067 was kind of an arrogance when they came into bioethics. Many of us are proud of
2068 the fact that we came in and actually were there when these things were
2069 happening. We thought we knew.

2070

2071 Swazey: One memory that has always stayed with me is the Hastings task force on
2072 newborn intensive care. I was on that for awhile. I went to the first meeting and
2073 looked around and said, "There aren't any neonatologists in this group." And the
2074 response was, "We don't need any, we have physicians in the group." It was Bob
2075 Morison and Will Gaylin. And me as a social scientist, that didn't cut it.

2076

2077 Jonsen: That's appalling, it really is! But that's true. I respect Bob Veatch's work very
2078 much but Bob's never spent any time in the clinical setting. And so maybe if I say
2079 people in bioethics thought they knew all the facts, I'm really referring to myself.

2080

2081 Back in the days when I was first starting out, there were some
sociological studies that I read and hated. I never could appreciate Freidson's

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2082 work. But I was incredibly enriched by Anselm Strauss' work. I really learned a
2083 lot from Strauss and from Diana Crane, in particular. Your books with Renée
2084 were very illuminating to me. I guess the difference for me is that it seemed like
2085 Freidson was sitting there thinking this thing out about professional domination
2086 and then going out and giving some examples of it and refining the idea and so
2087 forth and so on. Whereas, these other books were really rich with the sense of
2088 what was actually going on. So I couldn't imagine doing bioethics without that
2089 sort of thing, although I never systematically found a way to include it. Some of
2090 my students, early on, wanted to do bioethics and sociology and anthropology,
2091 like Barbara Koenig, and the person who did that nice book on neonatal intensive
2092 care, Rene Anspach. That had a lot to do with how we think casuistically. When
2093 you have a good sophisticated analysis of such things as the levels of power
2094 within a particular setting, not in the big overall world that Freidson was talking
2095 about, but in this nursery where the physicians and the residents are relating to
2096 each other, and somebody describes that, then it becomes casuistically relevant.

2097

2098 Swazey: It seems to me that there is a lot of synchrony between casuistry and participant
2099 observation.

2100

2101 Jonsen: That's right. I think there's more natural affinity between casuistry and
2102 participant observation in the social sciences than there is between casuistry and

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2103 narrative ethics which people are trying to do today. Narrative ethics, to me,
2104 rambles on and on and on. Participant observation essentially says, “You can
2105 ramble on and on and on, but you’ve got to find structure.”

2106

2107 Swazey: Do we have time to talk about clinical ethics?

2108

2109 Jonsen: Yes.

2110

2111 Swazey: You certainly had a good review of the fourth edition of Clinical Ethics in
2112 The New England Journal. The first broad question is what you see as the role of
2113 the person who’s called a clinical ethicist. It seems to me they obviously are not
2114 always dealing with the dramatic life-or-death decision type of case.

2115

2116 Jonsen: My view of clinical ethics and clinical ethicists is obviously shaped by my own
2117 experience. I believe that a clinical ethicist is an educator. I came into this kind
2118 of work as a professor of ethics in the medical school, realizing that we didn’t
2119 have an entrée to students by way of formal courses. It seemed to be a good thing
2120 to try to educate them at the level of their clinical experiences. As I mentioned to
2121 you yesterday I had a very good entrée in neonatology, and I had a very good
2122 entrée into the intensive care unit, and also in the cancer service and in high risk
2123 pregnancy groups. The educational role that I was playing there was to simply

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2124 help everybody involved in the situation work through the ethical aspects of cases
2125 that came up. So it was, in my view, clinical education with regard to ethics. And
2126 the structure of the book, Clinical Ethics, came out of that experience. It was an
2127 attempt to structure conversation in a way that would highlight and focus on the
2128 ethical problem in a case. It was almost always in the presence of several medical
2129 students doing their clerkship, more house officers than students usually, and the
2130 nurses and the attendings. But it was largely educational, so I never thought of
2131 myself as being a decision maker or giving people advice about decisions. It was
2132 simply to try to sort out the various features of the case that had some bearing on
2133 the ethical problem that people were thinking about. A second source of the
2134 structure of that book was in the initial Ethics Committee at UCSF which the
2135 chancellor had asked me to chair. We found ourselves, in those early days,
2136 without any way of giving structure to the kind of cases that we were asked to
2137 review. So the idea of what has come to be called “the four boxes” in clinical
2138 ethics came out of trying to give structure to a case that would allow people to
2139 look at all its features. So I’ve always thought of clinical ethicists as educators,
2140 not as advisors, not as consultants.

2141

2142 Swazey: Including patients and families in that educational orbit?

2143

2144 Jonsen: Well, I have not done that personally. I think there’s a good case to include

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2145 families but the reason why I have not done it habitually, (I've done it from time
2146 to time) is that I strongly believe that the relationship between the physician or
2147 whatever health care provider it is, and the family-patient that they were dealing
2148 with, that the relationship needed to be very clear and that I shouldn't intervene in
2149 it. So I felt that if I could help the health care provider formulate the issues, that it
2150 was up to them to bring those to the family. It would happen from time to time
2151 that the providers would say, "Let's bring the family in and talk with them about
2152 it." I would always be glad to be there but I didn't want to be the primary
2153 spokesperson. I think that's the doctor's job.

2154
2155 Swazey: Did you generally have a fairly high level of confidence that after you had done
2156 your educator role with a physician he would in fact be able to lay out those issues
2157 for the family?

2158
2159 Jonsen: I never knew, I never really knew. I had confidence in the people that I used to do
2160 this with regularly. With the ad hoc consultations you never knew what it was
2161 when they went away and they'd say, "That's great, that's a great way to analyze,
2162 a good way to put it." How that actually came out at the next phase, I don't know.
2163 And I've never kept a record of it but I do know that on occasion I would hear
2164 from other parties like the nurses saying, "Dr. so and so walked out of here saying
2165 he was going to do such and such and he did just the opposite." More frequently

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2166 than that I think...what happens is that the analysis given in these consultations
2167 seem pretty good to everybody but the circumstances would change fairly rapidly.
2168 The patient would get better, or the patient would die, or whatever, or something
2169 new would come along that would change the circumstances. So I thought of it,
2170 again, as an exercise in improving people's ability to perceive what was at stake in
2171 these questions. I think a lot of people have learned that perception and do learn
2172 that. How they actually bring it to bear in a real situation, I'm never quite sure of.
2173 I know now that in a number of places it's being used as a tool to explain to
2174 families what the situation is. I was out at a big nursing home the other day where
2175 they said they have used "the four boxes" for years as their format for explaining
2176 to families what the situation is. They sit down with the family, they go through it
2177 with the family, they fill out "the four boxes", they give the family a copy of it.
2178 Then if an issue has to be discussed, like resuscitation, the family comes back and
2179 says, "Let's look; let's see what's changed." Children's Hospital here and its
2180 hospice service uses it that way. St. Paul's Hospital in Vancouver in the critical
2181 care unit, uses it. I never conceived it in that way and yet it seems to be very
2182 valuable in simply laying out what the case is.

2183

2184 Swazey: I would think it would be particularly useful in a hospice unit or a long-term care
2185 facility where you have interactions over time as opposed to two days in the
2186 hospital.

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2187 Jonsen: Yes, that's right. So I don't have a very romantic view of clinical ethicists. I
2188 certainly don't see them as going around with white coats second guessing. They
2189 rarely have the scope of knowledge necessary at the clinical level to be
2190 particularly helpful. They bring two things to bear if they do it well. The first is
2191 some sort of clear and very practical analytic method, whether it's Dave
2192 Thomasma's ethical workup or the four boxes, or whatever. They've got some
2193 way of doing this in an unobtrusive and subtle way of ordering the issues to put
2194 the focus on what the ethical problems are. And the second thing they bring to
2195 bear is a treasury of other cases that are like this one. That comes either from their
2196 own experience with similar cases, or from the literature, or from the law. So that
2197 if you're a good clinical ethicist, you tap into that store of information which the
2198 best clinician may not have. They usually have their set of experiences
2199 themselves but they don't have the kind of precedent view of cases. Also,
2200 ethicists can refer to certain sorts of arguments that have been made one way or
2201 the other. I gave grand rounds to orthopedic surgeons the other day. And lo and
2202 behold, in the question period somebody brings up the Lorber criteria. An older
2203 physician said, "When I was a Fellow back in the 1950's, I studied in England.
2204 There was this physician in England that was setting out these criteria for surgery
2205 for kids with spina bifida." And he went on to draw some conclusion about it and
2206 because I knew Lorber and his work I was able to put that whole thing in context
2207 right away.

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2208 Swazey: It doesn't seem that long ago but I guess it was!

2209

2210 Jonsen: Yes it was.

2211

2212 Swazey: So having said that, who should be eligible to be a clinical ethicist, or do clinical
2213 ethics? What competencies?

2214

2215 Jonsen: First of all, it ought to be somebody who has common sense and humility. I think
2216 those are the primary affective characteristics. Well, common sense isn't
2217 affective, but humility is affective. And I think it ought to be someone who has
2218 mastered the extant and relevant literature. There is a canon that it's important to
2219 have hold of.

2220

2221 Swazey: Canon of cases as well as moral reasoning?

2222

2223 Jonsen: Yes, and theory is not a part of that canon.

2224

2225 Swazey: I hear you!

2226

2227 Jonsen: And then I think you have to have a practical frame of mind. That is, you cannot
2228 leave that sort of encounter by simply saying, "Well, this is a tough problem," or

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2229 make the problem more complex in people's minds than it was when they came
2230 in. I remember Larry McCullough saying years ago at a meeting, "I was trained as
2231 a philosopher, and a philosopher's job is to make problems more complicated than
2232 they appear to be." You can't do that as a clinical ethicist.

2233

2234 Swazey: That certainly is not what either care givers or families need.

2235

2236 Jonsen: No, by no means! And it indeed may be complicated and one of the first things
2237 you do is to disabuse people of the simplicity of the case. But you can't go away
2238 leaving them with this open-ended sense of "there are all sorts of options out
2239 there and I don't know which is better than another." You should give people a
2240 sense that there are options but they are valenced ones. Each option has a set of
2241 arguments around it which give it a greater or lesser valence in the minds of the
2242 people who are listening to it. So when you go out and speak with a family, you
2243 may say, "Well, the primary thing is what the family decides, and here is what we
2244 think we ought to do." But when you offer the family these options, give them
2245 some sense of the strength of those options.

2246

2247 Swazey: So somebody who comes out of one of the burgeoning number of masters
2248 programs in bioethics, are they ready to be a clinical ethicist?

2249

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2250 Jonsen: Probably not. I would imagine that the first thing that they would do is to feel that
2251 they have the tools to do that sort of thing but they don't, because they probably
2252 don't have the humility. There probably, ideally, ought to be apprenticeships and
2253 mentorships in clinical ethics, which I guess don't exist very much. So that
2254 someone who has achieved a reputation for doing it well can pass on, in a critical
2255 way, the kind of techniques that are useful. If you go back to what I said in the
2256 beginning, I think of it as an educational activity. Education has its techniques.
2257

2258 Swazey: Certainly, it seems to me, if anybody is going to make it even more complicated
2259 than it is, it's going to be the fledgling person with their newly minted MA who
2260 has to impart every nuance he or she can think of. Which I think most of us do
2261 when we teach for the first time. "Boy, we'd better give them every nugget we've
2262 ever learned or we're failing."
2263

2264 Jonsen: Everything, yes. You remember when you start teaching and you draw up a plan
2265 for a lecture and it's always four times longer than the time you have.
2266

2267 Swazey: Absolutely, so you speak very fast! Unintelligibly!
2268

2269 Jonsen: Since a lot of those people with MAs in bioethics are health professionals, that's
2270 probably an additional problem because particularly physicians, almost

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2271 exclusively physicians, will go into clinical bioethics with the same kind of
2272 authoritarianism. So they will lack the humility.

2273

2274 Swazey: What about the certification-licensure debate? I guess I've never been able to
2275 quite figure out how you would certify somebody.

2276

2277 Jonsen: I'm not a great fan. I haven't read the certification report that Bob Arnold and
2278 others did, so I don't know what they say. I've never been a strong fan of
2279 certification in that sense. We do give a certificate, but the certificate is simply a
2280 way of saying a person has had such and such a block of education. It doesn't
2281 certify the set of skills that are necessary to do ethics consultation or clinical ethics
2282 because those skills go beyond the educational, as such. I rather think that it will
2283 get sorted out. There's a lot of sorting out that goes on in our world of health
2284 care. People come, and no matter whether they're big surgeons or techs, and they
2285 get tested and their testing pushes them aside or brings them to the center. I think
2286 that's what will happen with a lot of these people. They'll go out and some of
2287 them will do it well and they'll be acknowledged, and others will be pushed out.
2288 I've seen that happen; there are people who started out in the field and the
2289 characteristic they had was a kind of an imperiousness, that they knew everything.
2290 Then the next thing you notice...I'm talking about lay persons...next thing you
2291 know they were consultants. They were no longer employed by the place that

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2292 employed them but they were private consultants, and then they disappear from
2293 view.

2294

2295 Swazey: That's a good eliminating process...natural selection.

2296

2297 Jonsen: Yes, it's natural selection. I hope it will work that way.

2298

2299 Swazey: Time will tell. Let me ask you a quick final question. Where do you see bioethics
2300 going in the future? Does it have new areas to get into?

2301

2302 Jonsen: I could simply say, apres nous le deluge. I think the mining of old subjects does
2303 take place within a context of new developments, to some extent. There is a
2304 history to these things. It isn't just going over old territory, the territory changes
2305 to some extent. I think in the area of death and dying, which is a constant, we
2306 have seen changes in the social setting of those problems and in the technological
2307 and so forth. So that area will, I think, be a continual issue. I think, in general,
2308 that bioethics will remain around simply because of the complexity of the health
2309 care world. It is, in a sense, a creature of bureaucratic complexification. I
2310 suppose it's a kind of a Weberian phenomena. The system has gotten so big and
2311 so complex that this little bioethics thing kind of grows on it, taking up a set of
2312 questions that are urgent, real questions that nobody else has the time or the

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2313 assignment to take up. I guess that's the Weberian part of it, that bioethicists have
2314 an assignment to take up a set of questions and to keep producing responses to
2315 them. And I think the managed care phenomenon, which we'll probably be
2316 struggling through for at least ten years, will give a certain amount of space to the
2317 bioethics activities. If we do have a patients' bill of rights passed by the
2318 Congress, that's going to mean a certain amount of business for people in
2319 bioethics because all that stuff will have to be turned into policy and applied and
2320 so forth. And it's natural for somebody to say, "Let's get an ethics person to do
2321 it." The managed care people are already getting ethics people to do it! If a
2322 patient's bill of rights isn't passed, all the problems that it was supposed to
2323 address will still be there. That also leads the way to having some people doing
2324 this general bioethics set of activities. I think the genetics advances and new
2325 things in transplantation, like xenotransplantation, will also provide a set of
2326 issues. And I think that the medical schools will continue to do what they have
2327 always done, sponsoring teaching. And then finally, I think that there is, at the
2328 present time, for the last few years, a growing interest in ethics in a lot of other
2329 places. Bioethics is the grandparent. Journalistic ethics, and business ethics, and
2330 ethics in the arts, and all this kind of stuff is starting to happen and getting
2331 formalized within the university settings; something similar to what happened to
2332 bioethics 25 or 30 years ago is starting to happen in those areas. And among those
2333 people, there is an interest in learning what bioethics has learned in order to bring

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2334 it to bear in their setting. How much do you have to have of formal ethics? How
2335 much do you have to be a philosopher? We've got a nice little group of people
2336 here doing ethics in other places and we communicate and talk about those things.

2337

2338 Swazey: Sort of an ethics across the professions.

2339

2340 Jonsen: Yes, we call it The Ethics Alliance. And so I think that will also contribute to the
2341 continuance of this grandparent of ethics in the professions. I think it will be
2342 around and I think that it will change with the changing health care scene, with
2343 new developments in technology, but it will also change with the growing
2344 introduction of feminist ethics. I think that the cross-cultural issues are interesting
2345 enough and fascinating enough that it will bring some fresh thinking into the field
2346 and expand it; that's very much on the fringes now. That's a rough cut.

2347

2348 Swazey: Sounds like a reasonable one, it will be interesting to see. You have certainly
2349 given me a great deal of time, and thought, and thoughtfulness.

2350

2351 Jonsen: It's my pleasure, Judy. I've enjoyed talking with you very much.

2352

2353 END OF INTERVIEW

2354